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Supplementary File

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Glossary

Acquired life potential (ALP): A measure of how far a fetus has acquired the characteristics that make losing future life bad for it.

Cost-effectiveness analysis (CEA): an analytical tool in which costs and effects of a program and at least one alternative are calculated and presented in ratio of incremental cost to incremental effect. Effects are health outcomes, such as cases of a disease prevented, years of life gained, or quality adjusted life years, rather than monetary measures as in cost-benefit analysis.

Cost-effectiveness ratio: the incremental cost of obtaining a unit of health effect (such as dollars per year, or per quality-adjusted year, of life expectancy) from a given health intervention, when compared with an alternative.

Direct costs: the value of all goods, services, and other resources that are consumed in the provision of an intervention or in dealing with the side effects or other current and future consequences linked to it.

Disability-adjusted life years (DALYs): an indicator developed to assess the global burden of disease. DALYs are computed by adjusting age-specific life expectancy for loss of healthy life due to disability, which is assigned a weight from 0 (full health) to 1 (equivalent to death).

Time discounting: Process applied to costs or benefits to represent higher value placed on a good received at an earlier time.

Discount rate: the interest rate used to compute present value, or the interest rate used in discounting future sums.

Economic Evaluation: the comparison of two or more alternative courses of action in terms of their costs and consequences.

Health-related quality of life (HRQOL): the impact of the health aspects of an individual's life on that person's quality of life, or overall well-being. Also used to refer to the value of a health state to an individual.

Indirect costs: the value of output, lost productivity or forgone resources incurred from time off work due to morbidity or disability following an illness], and intangible costs

Intangible costs: non-monetary costs reflecting the 'disvalue' to an individual for example: pain, anxiety, fear and suffering

Quality-adjusted life years (QALYs): measure of health outcome which assigns to each period of time a weight, ranging from 0 to 1, corresponding to health-related quality of life during that period, where a weight of 1 corresponds to optimal health, and a weight of 0 corresponds to a health state judged equivalent to death; these are then aggregated across time periods.

Quality of life: broad construct reflecting subjective or objective judgement concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic, and spiritual aspects.

Time preference: rate at which the decision maker is just willing to trade present for future consumption of some commodity of interest. A positive rate of time preference means the decision maker is willing to forgo some current consumption of the commodity in return for a sufficiently large gain in future consumption.

Detailed Methods

Systematic review of economic costs of stillbirth

The searches conducted for the review by Mistry et al. (2013) were repeated in order to identify any new and relevant papers.¹ In the original review searching was restricted to articles published in English language and to humans between January 1998 to October 2013. The same searches were carried out but without restrictions and the last search was carried out on 26 January 2015. The following databases were searched: MEDLINE, EMBASE, CINAHL, LILACS and Web of Science by TER and AH. An example of a search strategy is shown in Box 1. Studies which described resource use and costs (in monetary terms) associated with stillbirth were included. Studies were excluded if it was not possible to differentiate between stillbirths and other forms of pregnancy loss or child death e.g. first trimester miscarriage or if resource use was not quantified. The same two-stage screening process as previously employed was used to select papers for the review. An example of the search strategy is shown below.

1. stillbirth/
2. stillbirth\$.mp.
3. fetal death/
4. perinatal loss.mp.
5. pregnancy loss.mp.
6. perinatal death.mp.
7. or/1-6
8. exp "costs and cost analysis"/
9. exp health care costs/
10. economics/
11. budget\$.tw.
12. or/8-11
13. 7 and 12

Systematic review of the economic costs in subsequent pregnancy

The review follows a rigorous multi-stage methodology and took into account the guidance provided by the Centre for Reviews and Dissemination (CRD).² Database searches were initially used to identify relevant information. Although many articles were identified around stillbirth none provided

cost or utilisation data. This resulted in the use of the Pearl growing technique. This relies primarily on identifying articles through important key papers and subsequent citation searching of these articles.

The following PICO format was used to identify studies for the review which ensured broad identification of relevant papers: Population - women who have history of stillbirth and are currently pregnant or are planning a subsequent pregnancy, Intervention - any treatment received as a result of 'high risk' pregnancy, Comparator - normal pregnancy care, Outcomes – i) any cost impact on health services, ii) any cost impact on society. Books were excluded from the review due to time restrictions. There were no language restrictions placed but identified articles that were written in another language were excluded from the analysis. Any duplicate articles were identified and removed through Refworks.

The search strategies that were used to undertake this review were relevant to each individual database and were highly reflective of the review in question. Important key words were identified through articles provided by experts in the research area. Phrases, synonyms and indexing terms were then identified using the medical subject heading (MeSH) thesaurus in PubMed, subsequently to be used in each database. Modifications were made to each search strategy to best match and reflect the subject headings in each database. Truncation terms were not used, however explode functions and Boolean operators were applied where relevant. Databases included in the review: MEDLINE, CINAHL, EconLit and Health Management Information Consortium (HMIC). Searches were conducted in January 2015. An example search strategy is shown below:

1. Stillbirth/ec [Economics]
2. Fetal Death/co, ec, mo, pc, sn [Complications, Economics, Mortality, Prevention & Control, Statistics & Numerical Data]
3. Pregnancy Outcome/ec, pc, sn [Economics, Prevention & Control, Statistics & Numerical Data]
4. Infant Mortality/
5. Perinatal Mortality/
6. Pregnancy Complications/
7. Death/
8. Reproduction/

9. Pathologic Processes/
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. "Costs and Cost Analysis"/ec, sn, ut [Economics, Statistics & Numerical Data, Utilization]
12. cost comparison.mp.
13. Cost-Benefit Analysis/
14. cost minimisation.mp.
15. "Weights and Measures"/
16. "Cost of Illness"/
17. Health Care Costs/
18. Hospital Costs/
19. societal costs.mp.
20. healthcare expenditure.mp.
21. Economics, Hospital/
22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23. 10 and 22
24. limit 23 to humans

To categorise manuscripts the titles and abstracts were read and the articles were categorised into eight different group's dependant on their relevance. The categories were as follows:

- A. The study contains cost or utilization data on subsequent pregnancies after still birth,
- B. The study looks into patient reports to determine cost or utilization of healthcare resources
- C. The study discusses how these patients should be treated, i.e. whether they should be treated as High risk or normal patients and be given relevant treatment. Or it provides care pathways relevant to management of pregnancy subsequent to stillbirth.
- D. The study determined from a qualitative angle what the patients or their partners would like to receive in terms of treatment to better enable them to have a normal full term pregnancy
- E. The study categorizes still birth with other prenatal conditions as one condition and costs treatment of these conditions and provide either, costs, utilization or treatment protocols
- F. Stillbirth information presented that is useful but based on expert opinion
- G. The study is useful but doesn't fall into any above category, may be useful for other aspects of the review
- H. The title and/or abstract is not relevant for this review

Studies were subsequently sub-grouped into eight further areas to provide better description of the study, these were:

1. Cost analysis or cost description
2. Utilization data
3. Retrospective cohort/cost study /Descriptive study
4. Economic evaluation
5. Effectiveness study: increased antenatal visits could provide better outcomes so may in turn show better effectiveness
6. Qualitative/Ethnographic study
7. Informative study on stillbirths
8. Foreign language; for exclusion

As database searches proved unfruitful for the systematic review, other methods (The PEARL technique) were subsequently employed. A key paper provided by an expert in the field (AH) was used to bolster the investigation using this method. Web of Science was used to citation search one key article which was found in the reference list of the index manuscript.¹ This paper by Reddy (2010)³ was read in full, and the reference list was also searched to identify any other relevant manuscripts. All identified manuscripts were read in full to determine whether they met the inclusion criteria. Identified studies were categorised and data extracted. This primarily concerned the proposed management pathway for pregnancy following stillbirth. Costs were then applied to each of the components of the care pathway, these were reported in their original currency but inflated to 2013 prices for comparison.^{4, 5}

Systematic review and metasummary of the psychological and social impact of stillbirth on parents

Medline, PUBMED, Embase, Scopus, Amed, BNI, CINAHL and PsychINFO together with conference abstracts from Royal College of Obstetricians and Gynaecologists and International Stillbirth Alliance conferences were searched from January 2000 to February 2015, using the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, Research type)⁶ and following the PRISMA guidelines.⁷ Qualitative, quantitative and mixed methods studies were included assessing the psychosocial effects of stillbirth on parents, grandparents and siblings. An example of the search strategy is illustrated below.

**subject headings varied between databases but covered the same topic/concept.

Stillb*

1. "intrauterine death*"
2. "intra-uterine death*"
3. "in utero death*"
4. IUD
5. IUFD
6. "foetal loss*"
7. "fetal loss*"
8. "foetal death*"
9. "fetal death*"

10. "foetal demise*"
11. "fetal demise*"
12. "perinatal death*"
13. STILLBIRTH/
14. FETAL DEATH/
15. PERINATAL MORTALITY/
16. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16
17. Coil*
18. Device*
19. Mirena
20. 18 or 19 or 20
21. 17 NOT 21
22. Psychosocial
23. Social*
24. Anxiety
25. Depress*
26. Stress*
27. Distress*
28. Panic*
29. PTSD
30. Suicid*
31. Grief*
32. Griev*
33. Resent*
34. Guilt*
35. Sex*
36. Psychosex*
37. Exp PSYCHOLOGY, SOCIAL/
38. Exp INTERPERSONAL RELATIONS/
39. Exp ANXIETY/
40. Exp ANXIETY DISORDERS/
41. DEPRESSION/
42. Exp MOOD DISORDERS/
43. PANIC/
44. PANIC DISORDER/
45. SUICIDE/
46. SUICIDE, ATTEMPTED/
47. Exp EMOTIONS/
48. Exp SEXUAL DYSFUNCTIONS, PSYCHOLOGICAL/
49. SOCIAL ISOLATION/
50. 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50
51. Mother*
52. Mum*
53. Father*
54. Dad*
55. Parent*
56. Grandparent*
57. Couple*
58. Husband*
59. Wife

- 60. Wives
- 61. Spous*
- 62. Child*
- 63. Sibling*
- 64. Family
- 65. Families
- 66. Communit*
- 67. Exp FAMILY/
- 68. Exp PARENTS/
- 69. 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69
- 70. 22 AND 51 AND 70

Combining search results provided an initial screen. On the basis of abstracts, studies were excluded by four investigators (CB, SB, CS and DS) if they were: a) duplicates, b) topic not relevant to stillbirth, c) impact on healthcare professionals, d) review articles, e) year of publication, f) dissertations, or g) intervention studies. Reference lists were scanned for additional studies. This generated a list of potential full text papers, which were obtained and assessed separately by two investigators (CB and SB). Further papers were excluded using the same criteria, and also if h) personal accounts, i) no findings found in data, and j) papers requiring complex translation, k) paper unavailable. Disagreements on whether to include or exclude papers were discussed between the wider research team to reach consensus. We sought any unclear or missing information by contacting the authors of the individual studies. The findings were extracted from the final papers by two investigators (CB & SB).

Finally, the meta-summary method (Sandelowski) was followed.⁸ A core investigator group (CB, SB, CS, DS, and AE) summarised the findings in thematic sentences, and a further investigator with psychology qualifications (JC) revised the wording of the sentences. The investigators calculated Frequency Effect Sizes for each theme/sentence (FES – the proportion of studies including findings from each theme). This provides a guide for the prominence of a given finding in the reviewed literature.

Systematic review and metasummary of the impact of stillbirth on health care professionals

We conducted a systematic search on the psychosocial impact of stillbirth on health care professionals, using seven databases for searching: EMBASE, MEDLINE, PSYCHINFO, CINAHL, AJOL, LILACS, and CNKI. We limited results to articles which were research-based (no clinical articles or case studies), had been published in peer-reviewed literature (no dissertations), were published in 2000 or later, and allowed us to separate out the impact of stillbirth if the broader study had combined impact of multiple types of deaths such as perinatal or infant. We included articles in any language. Searches were conducted between January 27 and March 6, 2015.

In general, the search strategy combined words which would identify a stillbirth, terms to identify different types of health care professionals, and words which described coping strategies, reactions, or psychosocial responses. Since each database used different indexing terms, the exact search query varied (Table 1). Relevant abstracts and articles in languages other than English were translated for review or analysis. Search terms were reviewed by two authors (K.J.G. and D.N.). K.J.G. conducted the actual searches. Abstracts were reviewed by the same two authors with any disagreements resolved by consensus. The final list of 49 manuscripts were reviewed and coded in full by three authors (D.N., K.O., J.C.); no manuscript was excluded from the study unless at least two authors had reviewed it.

Table 1: Search Strategy for Psychosocial Impact of Stillbirth on Health Professionals.

Database	Stillbirth Terms	Hits
AJOL	(stillbirth OR still birth or stillborn or IUFD or perinatal death or perinatal loss or fetal death or fetal demise or fetal mortality or perinatal mortality or perinatal death) AND (doctor* or nurse* or midwi*)	
CINAHL	S1 stillbirth OR intrauterine death OR perinatal death OR dead baby in utero S2 stillbirth* OR stillb* S3 intrauterine death S4 intrauterine death OR intrauterine fetal demise OR intrauterine fetal death S5 "intrauterine death" S6 IUFD S7 intra-uterine death S8 "intra-uterine death" S9 still born OR still-born baby OR still-born infant OR still-born births S10 still birth S11 foetal loss OR fetal loss	

	<p>S12 foetal death OR fetal death</p> <p>S13 foetal demise OR fetal demise</p> <p>S14 foetus death OR fetus death</p> <p>S15 foetal mortality OR fetal mortality</p> <p>S16 perinatal loss OR perinatal death OR perinatal mortality OR peri natal loss OR peri natal death OR peri natal mortality OR peri-natal loss OR peri-natal death OR peri natal mortality</p> <p>S17 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16</p> <p>S18 physician* OR physician assistant* OR physician-patient* or physician patient*</p> <p>S19 doctor* or doctor-patient* OR doctor patient*</p> <p>S20 medical school faculty OR physician faculty OR physician-faculty OR medical faculty</p> <p>S21 nursing school faculty OR nurse-faculty* OR nurse faculty</p> <p>S22 nurse* OR nurse practitioner OR nursing staff OR obstetric* nurs*</p> <p>S23 obstetrician* OR obstetrical provider OR family physician</p> <p>S24 hospital staff* OR hospital personnel OR medical staff OR medical personnel OR health care personnel OR allied health professionals OR allied health personnel</p> <p>S25 social worker* OR doula OR midwi* OR nurse midw*</p> <p>S26 coroner* OR medical examiner OR emergency responders*</p> <p>S27 chaplain* OR clergy* OR priest OR imam OR (rabbi or rabbis) OR spiritual care provider OR spiritual caregiver OR pastoral care</p> <p>S28 mortuary staff OR mortuary personnel OR mortician* OR funeral staff OR funeral director</p> <p>S29 ambulance staff OR ambulance personnel OR ambulance drivers</p> <p>S30 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29</p> <p>S31 depression* or mental stress* OR mental distress* OR psychological distress</p> <p>S32 anxiety* OR ptsd* OR post-traumatic stress disorder OR posttraumatic stress disorder OR traumatic stress</p> <p>S33 spiritual stress OR spiritual distress OR burnout</p> <p>S34 coping* OR resilien* OR spiritual well-being OR psychology* adapt*</p> <p>S35 attitude of health personnel OR health personnel attitudes</p> <p>S36 S31 OR S32 OR S33 OR S34 OR S35</p> <p>S37 coil* OR mirena* OR paragard OR iud* OR iud intrauterine devices OR abortion OR spontaneous abortion OR miscarriage OR veterinary* OR device*</p> <p>S38 S17 and S30 and S36</p> <p>S39 S38 NOT S37</p>	
CNKI	AB=(stillbirth + 'still born' + stillborn + 'perinatal death' + 'fetal death' + 'fetal loss' + 'fetal demise' + IUFD) * (physician + doctor + nurse + staff + midwife + obstetrician)	41
EMBASE	<ol style="list-style-type: none"> 1. stillbirth* 2. intrauterine AND death OR perinatal AND death OR dead AND baby AND in AND utero 3. stillb* 4. 'intra-uterine death' OR intrauterine AND death 5. in AND utero AND death OR iufd 6. 'foetal loss' OR 'fetal loss' 7. foetal AND loss 8. fetal AND loss 9. 'fetal death' OR 'foetal death' 10. fetal AND death 11. foetal AND death 	

12. 'fetal demise' OR 'foetal demise'
13. fetal AND demise
14. foetal AND demise
15. perinatal AND death*
16. perinatal AND mortality
17. still AND birth*
18. still AND born
19. 'fetal mortality' OR 'foetal mortality'
20. fetal AND mortality
21. foetal AND mortality
22. 'fetus death' OR 'foetus death'
23. fetus AND death
24. foetus AND death
25. 'peri natal' AND mortality
26. 'peri natal' AND death*
27. #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12
OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22
OR #23 OR #24 OR #25 OR #26
28. coil* OR device* OR mirena* OR paragard* OR intrauterine AND device*
29. intrauterine AND contraceptive AND device
30. miscarriage OR abortion OR spontaneous AND abortion
31. veterinary* OR veterinary*
32. #28 OR #29 OR #30 OR #31
33. physician*
34. physician AND patient
35. physician AND patient AND relation*
36. doctor AND patient AND relation*
37. doctor AND patient
38. nurse*
39. nurse AND patient AND relation*
40. nurse AND patient
41. 'doctor' OR 'physician' OR 'nurse'
42. physician AND assistant*
43. nurse AND practitioner*
44. nurse AND midwi*
45. midwi*
46. health And personnel*
47. allied And health AND personnel*
48. caregiver*
49. nursing AND staff
50. medical AND staff
51. physician AND staff
52. 'nursing school faculty'
53. 'medical school faculty'
54. nursing AND faculty*
55. medical AND school AND faculty
56. nursing AND school AND faculty
57. doula*
58. obstetric* AND provider*
59. -----?
60. Hospital AND personnel
61. obstetrical AND nursing
62. chaplain
63. clergy*
64. priest

65. imam
66. rabbi*
67. spiritual AND caregiver
68. spiritual AND carer*
69. pastoral AND care
70. coroner*
71. medical AND examiner*
72. funeral AND director
73. funeral AND staff
74. mortuary AND personnel
75. mortuary AND staff
76. 'posthumous care'
77. ambulance AND worker
78. ambulance AND personnel
79. ambulance AND staff
80. obstetrician*
81. family AND physician*
82. general AND practitioner*
83. pediatrician*
84. #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83
85. depression*
86. anxiety*
87. mental AND stress*
88. psychological AND stress*
89. traumatic AND stress*
90. ptsd
91. post AND traumatic AND stress AND disorder*
92. posttraumatic AND stress AND disorder*
93. spiritual AND distress
94. 'spiritual wellbeing'
95. psychology* AND adaptation*
96. coping*
97. coping AND behavior*
98. burnout*
99. 'burnout syndrome'
100. health AND personnel AND attitude
101. #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91 OR #91 OR #92 OR #93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100
102. #27 AND #84 AND #101
103. #102 NOT #32
104. #103 AND ('clinical trial'/de OR 'cohort analysis'/de OR 'comparative study'/de OR 'controlled clinical trial'/de OR 'controlled study'/de OR 'human'/de OR 'interview'/de OR 'major clinical study'/de OR 'prospective study'/de OR 'questionnaire'/de OR 'randomized controlled trial'/de OR 'retrospective study'/de OR 'systematic review'/de) AND 'clinical trial'/lnk OR 'complication'/lnk OR 'congenital disorder'/lnk OR 'diagnosis'/lnk OR 'disease management'/lnk OR 'drug therapy'/lnk OR 'etiology'/lnk OR 'prevention'/lnk OR 'therapy'/lnk AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py) AND

[embase]/lim NOT [medline]/lim AND ('article'/it OR 'article in press'/it OR 'erratum'/it OR 'short survey'/it)	
LILACS	<p>(tw:(fetal death)) OR (tw:(fetal demise)) OR (tw:(foetal demise)) OR (tw:(foetal death)) OR (tw:(perinatal mortality)) OR (tw:(perinatal death)) OR (tw:(IUFD)) OR (tw:(stillbirth)) OR (tw:(fetal mortality)) OR (tw:(mortalidade fetal)) OR (tw:(muerti fetal)) OR (tw:(mortalidade perinatal))</p> <p><i>(search then limited to humans; main subject: perinatal mortality, cohort studies, fetal death, fetal mortality, pregnancy outcome, anxiety, stress-psychological, life change events; cohort study, case-control study, or controlled clinical trial; type: article, year: 2000-present)</i></p> <p>tw:(("fetal death" OR "IUFD" OR "fetal demise" OR "fetal mortality" OR "stillbirth") AND ("health manpower" OR "health personnel")) AND (instance:"regional") AND (year_cluster:("2000" OR "2001" OR "2002" OR "2003" OR "2004" OR "2005" OR "2006" OR "2007" OR "2008" OR "2009" OR "2011" OR "2012" OR "2013" OR "2014" OR "2015"))</p>
MEDLINE	<ol style="list-style-type: none"> 1. exp Stillbirth/ or Stillb*.mp. or exp Fetal Death/ 2. "intrauterine death*".mp. 3. "intra-uterine death*".mp. 4. "in utero death*".mp. 5. IUFD.mp. 6. "foetal loss*".mp. 7. "fetal loss".mp. 8. "foetal death*".mp. 9. "fetal death".mp. or exp Fetal Death/ 10. "foetal demise*".mp. 11. "perinatal death*".mp. 12. perinatal mortality.mp. or exp Perinatal Mortality/ 13. "still birth".mp. 14. "still born".mp. 15. fetal mortality.mp. or exp Fetal Mortality/ 16. foetal mortality.mp. 17. foetus death.mp. 18. foetus mortality.mp. 19. exp Perinatal Death/ 20. peri-natal death.mp. 21. peri-natal mortality.mp. 22. fetus death.mp. 23. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 24. exp Physician-Patient Relations/ or physician-patient.mp. 25. Physician*.mp. 26. exp Nurse Practitioners/ or exp Physician Assistants/ 27. exp Midwifery/ or exp Nurse Midwives/ or nurse midw*.mp. 28. (midwiv* or midwife*).mp. 29. exp Nurse Clinicians/ or nurse*.mp. 30. exp Nurse-Patient Relations/ or exp Nursing Staff/ 31. exp Obstetric Nursing/ 32. exp Nursing Faculty Practice/ or exp Faculty, Nursing/ or exp Faculty, Medical/ 33. exp Physicians/ 34. exp Nurses/ 35. nursing staff.mp. or exp Nursing Staff/ 36. medical staff.mp. or exp Medical Staff/

37. "obstetrical provider".mp.
38. obstetrician*.mp.
39. exp Obstetrics/nu [Nursing]
40. exp Physicians, Family/
41. exp Personnel, Hospital/ or hospital staff.mp.
42. health personnel.mp. or exp Health Personnel/
43. exp Chaplaincy Service, Hospital/ or exp Palliative Care/ or chaplain*.mp. or exp Clergy/
44. priest*.mp.
45. (rabbi or rabbis).mp.
46. imam.mp.
47. exp Pastoral Care/ or spiritual caregiver.mp.
48. spiritual carer.mp.
49. hospital clergy.mp.
50. religious personnel.mp. or exp Religious Personnel/
51. funeral staff.mp.
52. funeral director.mp.
53. (mortuary staff or mortuary personnel).mp.
54. emergency responder*.mp. or exp Emergency Medical Technicians/
55. exp Allied Health Personnel/
56. coroner.mp. or exp "Coroners and Medical Examiners"/
57. (ambulance staff or ambulance worker or ambulance personnel).mp.
58. exp Doulas/
59. exp Obstetric Nursing/ or obstetric nurs*.mp.
60. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59
61. exp Depression/
62. exp Stress, Psychological/ or mental stress*.mp.
63. exp Anxiety Disorders/
64. ptsd.mp. or exp Stress Disorders, Post-Traumatic/
65. traumatic stress.mp.
66. (spiritual stress or spiritual distress.mp.
67. (spiritual well-being or spiritual wellbeing).mp.
68. exp Burnout, Professional/ or burnout*.mp.
69. exp Adaptation, Psychological/ or psychology* adapt*.mp.
70. exp Resilience, Psychological/
71. coping*.mp.
72. attitude of health personnel.mp. or exp "Attitude of Health Personnel"/
73. 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72
74. 23 and 60 and 73
75. coil*.mp.
76. device*.mp.
77. exp Intrauterine Devices/ or intrauterine device*.mp.
78. exp Abortion, Spontaneous/ or exp Abortion, Induced/
79. miscarriage.mp.
80. exp Veterinary Medicine/ or veterinary*.mp.
81. 75 or 76 or 77 or 78 or 79 or 80
82. 74 not 81
83. limit 82 to (yr="2000 –Current" and humans and (**case reports** or classical article or clinical trial, all or clinical trial, phase I or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial or comparative study or controlled clinical trial or journal article or multicenter study or observational study or pragmatic clinical trial or randomized controlled trial or "scientific integrity review" or twin study or validation studies))

PSYCHINFO	S1 stillbirth OR intrauterine death OR perinatal death OR dead baby in utero
	S2 stillbirth* OR stillb*
	S3 intrauterine death
	S4 intrauterine death OR intrauterine fetal demise OR intrauterine fetal death
	S5 "intrauterine death"
	S6 IUFD
	S7 intra-uterine death
	S8 "intra-uterine death"
	S9 still born OR still-born baby OR still-born infant OR still-born births
	S10 still birth
	S11 foetal loss OR fetal loss
	S12 foetal death OR fetal death
	S13 foetal demise OR fetal demise
	S14 foetus death OR fetus death
	S15 foetal mortality OR fetal mortality
	S16 perinatal loss OR perinatal death OR perinatal mortality OR peri natal loss OR peri natal death OR peri natal mortality OR peri-natal loss OR peri-natal death OR peri natal mortality
	S17 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
	S18 physician* OR physician assistant* OR physician-patient* or physician patient*
	S19 doctor* or doctor-patient* OR doctor patient*
	S20 medical school faculty OR physician faculty OR physician-faculty OR medical faculty
	S21 nursing school faculty OR nurse-faculty* OR nurse faculty
	S22 nurse* OR nurse practitioner OR nursing staff OR obstetric* nurs*
	S23 obstetrician* OR obstetrical provider OR family physician
	S24 hospital staff* OR hospital personnel OR medical staff OR medical personnel OR health care personnel OR allied health professionals OR allied health personnel
	S25 social worker* OR doula OR midwi* OR nurse midw*
	S26 coroner* OR medical examiner OR emergency responders*
	S27 chaplain* OR clergy* OR priest OR imam OR (rabbi or rabbis) OR spiritual care provider OR spiritual caregiver OR pastoral care
	S28 mortuary staff OR mortuary personnel OR mortician* OR funeral staff OR funeral director
	S29 ambulance staff OR ambulance personnel OR ambulance drivers
	S30 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29
	S31 depression* or mental stress* OR mental distress* OR psychological distress
	S32 anxiety* OR ptsd* OR post-traumatic stress disorder OR posttraumatic stress disorder OR traumatic stress
	S33 spiritual stress OR spiritual distress OR burnout
	S34 coping* OR resilien* OR spiritual well-being OR psychology* adapt*
	S35 attitude of health personnel OR health personnel attitudes
	S36 S31 OR S32 OR S33 OR S34 OR S35
	S37 coil* OR mirena* OR paragard OR iud* OR iud intrauterine devices OR abortion OR spontaneous abortion OR miscarriage OR veterinary* OR device*
	S38 S17 and S30 and S36
	S39 S38 NOT S37

The list of codes was developed based on preliminary review of relevant articles and clinical and research experience of the investigators, all of whom work in the field of stillbirth and perinatal loss. A codebook was created, and codes were discussed and revised until a final list was identified. Manuscripts eligible for full review were coded for content analysis. All authors met to discuss the themes which emerged from the review and to complete the data analysis.

The themes from the manuscripts were grouped into 7 thematic areas and following further analysis of each manuscript consensus was reached by the authors to agree on 4 major themes – psychological impact, professional impact, need for support and positive impact. The data were then further analysed to calculate frequency effect sizes both of the major themes and of the sub-themes. Frequency effect sizes were calculated by taking the number of manuscripts containing a finding and dividing by the number of included manuscripts.

Search strategy for studies of parental and family experiences of stillbirth, and of what works to improve clinical and psychological outcomes

The terms use below are examples of those used across the included datasets, looking in titles and abstracts in the first instance. Keywords and MeSH terms were used, as well as phrases. Expanders and limiters were employed for most searches. Alternative spellings were used for most terms (not all given in the examples below) including fetal/foetal and labour/labor. The date limit was set for 1994 to 31st November 2014 (when the searches were run).

Databases included CINAHL, Medline, PsycInfo, LILACS, AJOL, Cochrane and Embase.

The phenomenon

Bereav* maternal bereavement* DELIVER*, BIRTH*, PARTURITION, PARTU* CHILD BIRTH, LATE PREGNANCY LOSS , INTRAUTERINE FOETAL DEATH, INTRAUTERINE FOETAL DEMISE INTRAUTERINE FETAL DEATH IUFD "inutero death" "intra-uterine death" fetus death, fetus mortality "foetal mortality" fetal demise, fetal loss "fetal death/" pregnancy outcome , peri-natal loss , peri-natal

outcomes , peri-natal mortality , peri-natal death , stillborn, stillbirth BABY ,FETAL, FOETAL FOETUS
FETUS , Perinatal outcomes

The population

MOTHER* FATHER* PARTNER* FAMILY PARENT* GRANDMOTHER*

The intervention (and related concepts)

Social care, social support SUPPORT GROUP , COUNSELLING PROGRAM, PSYCHOSOCIAL CARE,
VALUES, ATTITUDE, IMPROVED CARE, 'perinatal bereavement care' interpersonal relation*
EMPATHY, attitude* "perinatal nursing", care, midwifery services, perinatal services, "maternity
services" , good quality care , "services for mothers" , "maternity unit" , improved maternal care TI
"perinatal services" , improved matern* care services , midw* support services, "midw* services" ,
"postnatal care" , maternal health* , maternal welfare services , health care "perinatal care" ,
maternal and child nursing, maternity care* , "hospital* setting*" , "hospital* cost*" , hospital, care
giving, maternal health care services , maternity services "HEALTH PROFESSIONAL* ROLE" ,
OBSTETRICIAN GYNECOLOGIST, OBSTETRICIAN, OBSTETRIC* NURSE* , MATERNITY SUPPORT
WORKER* "MATERNITY NURSE*" MIDWIFE, "HEALTH CARE NURSE*" HEALTH CARE WORKER*
"HEALTH PROFESSIONAL*" HEALTH CARE PERSONNEL* I "HEALTH PERSONNEL" CARER CARE GIVER*
HEALTH CARE PROFESSIONAL FAMILY RELATION* HEALTH CARE PROFESSIONAL

The outcomes

PARENTAL REACTION, PSYCHOSOCIAL SEQUELE, PSYCHOLOGICAL EFFECT, MENTAL HEALTH IMPACT,
RECOVERY, PSYCHOLOGICAL DISTRESS, PSYCHOLOGICAL DISORDERS

'perinatal bereavement health' 'perinatal mental health' 'perinatal depression' psycho* disorder*
behavior mental health "psycho* outcome* "psycholog* effect* "psychological distress" "suicide,
attempt*" suicide "panic disorder*" panic "mood disorder*" depression, health* good health
"anxiety

disorders" anxi* psychosex* guilt* resent* GRIE*

STRESS* ANXIETY SOCIAL* PSYCHOSOCIAL* "GRIEVING PROCESS"

"SOCIAL DILEM*" LIFE EXPERIENCES "PTSD" parental reaction* "psychotherapeutic outcome"

"psychological effect" improve* health "recovery process" health, quality of life wellbeing, mental

health impact" Emotion, "emotional disturb*" , emotional trauma "emotional state" emotional

stability emotional responses "psychological needs" Experience ab ti mother experience* experience

of parent* mourning parental grie*" PARENT RELATION* MATERNAL FETAL RELATION*

Studies were included if they were primary research studies or a review of primary research studies and data were collected after 1994 (to reflect current practices in maternity care). Data were considered relevant if they related to the experiences of maternity care as reported by anyone affected, and/or comparative studies of interventions to improve outcomes for those bereaved by stillbirth. For the purposes of these studies stillbirth was defined as a loss of an infant before birth between twenty weeks to 43 weeks gestation. All studies reporting the views and experiences of groups other than mothers/parents, and/or those undertaken in LMIC settings were included. Studies were excluded if they were non-research papers, if the data are collected from the point of view of staff or others who are not the affected person, if the information collected was relevant to a subsequent pregnancy and studies only reporting negative experiences.

Quality assessments were undertaken and reported, using the most appropriate tool for the study design in each case, but studies were not excluded on quality grounds. We were aware that the two existing Cochrane reviews in this area did not find any good quality studies.^{9, 10} We therefore intended to summarise the full scope of data available in the research literature (of whatever quality) as a basis for generating hypotheses for future controlled studies in this area, rather than to provide a definitive effectiveness analysis.

The final papers that met the inclusion and quality criteria *were* included in the study. Based on mixed methods metasynthesis methodology, the qualitative and quantitative data were summarised

narratively, and then a general synthesis was developed across both sets of data for each of the following four topics:

- General data on 'what works'
- The views and experiences of specific population sub-groups
- Views and experiences of mothers/fathers/parents in low and middle income countries
- Evaluation of any programme or intervention specifically introduced to improve outcomes for those who have experienced stillbirth.

Secondary analysis of data from published studies

To obtain further information about intangible costs of stillbirth, two databases from previous studies of parents experiences after perinatal death were used to provide answers to ten questions derived following systematic review and meta-ethnography to identify inclusive themes (*Ogwulu, 2015, Submitted to BMC Pregnancy and Childbirth*). The ten questions were:

1. Did you experience any negative psychological feelings after your baby died?
2. Did your stillbirth affect your relationship with others (partner, siblings, friends, colleagues)?
3. How long did the effects in the first two questions last?
4. How soon after the stillbirth did you/your partner return to your previous routines?
5. On returning to work, would you say that you/your partner were working at your fullest productive capacity?
6. Were any supportive measures put in place by healthcare staff after you had a stillbirth?
7. Was this support timely, adequate and effective?
8. Did you seek medical treatment for any negative psychological effects connected with the stillbirth?
9. Was this paid for privately or through the NHS?

10. Did you seek legal support to deal with any consequences of the stillbirth?

The two databases were from the TEAR study (USA)¹¹ and Listening to Parents study (UK).¹²

The TEAR Study is a cross-sectional online survey of bereaved parents registered in an online support forum from June to October of 2010. The survey contained general demographics as well as several validated measures commonly used in research on psychological health, family functioning, and resiliency. Respondents were recruited via the internet and utilized Qualtrics survey software. The online support forum had 972 valid email members from 2009-2010. A total of 503 participants responded, a final response rate of 51.8%; of the respondents 216 (43%) had experienced stillbirth. The study was approved by the Institutional Review Board of Arizona State University, by the ethics committee of the participating non-profit organization, and all respondents gave informed consent. Descriptive statistical analysis was conducted with SPSS (Version 21, IBM, NY, USA).

The Listening to Parents study contacted parents following stillbirth or neonatal death by a postal survey. Two separate questionnaires were used, one for women who had a stillborn baby and another for women whose baby died as a new-born, so that the questionnaires addressed appropriate issues for each group. Questions covered pregnancy, labour and birth, and the postnatal period and care at the time of the baby's death. Questions were mostly structured, but allowed for longer open text responses where appropriate. Before being used in the survey, both questionnaires were tested in 10 cognitive 'thinking aloud' interviews with parents who had experienced a stillbirth or the death of their baby as a new-born and revised to take account of their comments. The Office for National Statistics (ONS) identified samples of women (excluding those aged under 16 years) who registered a stillbirth or neonatal death between 1st January and 31st March 2012 and between 1st June and 31st August 2012. Mailing was thus carried out in two waves. Women were sent an introductory letter and study information between six and nine months after the death of their baby; the letters were sent by ONS. Three weeks later a further letter, questionnaire and information leaflet were sent to each woman by ONS. An NPEU Freephone contact line was available for all women contacted. Questionnaires were returned directly to the National Perinatal

Epidemiology Unit (NPEU). A reminder letter and a further copy of the questionnaire were sent to women who had not responded after a further four weeks. Data were received from 473 parents who had experienced a stillbirth. Relevant information was extracted from the data using STATA (Version 13, STATA Corp, TX, USA).

Analysis of data from International questionnaire for the 2015 Lancet Stillbirth Series

Quantitative and qualitative data were extracted from a multi-language web-based survey of bereaved parents to assess parents' experiences of stillbirth and the quality of clinical and bereavement care provided. This survey was one of three developed to provide data for the 2015 Lancet Stillbirth Series; detailed information about each of the surveys is given in Paper 4.¹³ For this survey the target audiences was parents in HIC who had had a stillborn baby at any time. The study was approved by the Mater Health Services Human Research Ethics Committee, within the guidelines of the Australian National Statement on Ethical Conduct in Human Research and the University of British Columbia Office of Research Ethics.

Surveys were disseminated between December 2014 and February 2015 via the International Stillbirth Alliance member organisations. Further detail about dissemination of the surveys is not presented but is available from the authors on request. Due to the recruitment method adopted in this study, we could not determine the number of men and women who were exposed to the study advertisement, and therefore the overall response rate is unknown. To account for uneven distribution of responses across countries, quantitative data were weighted using following formula:

$$\frac{\text{Annual number of stillbirths/births in country}}{\text{Annual number of stillbirths/births in all participating countries}} \times \frac{\text{Number of respondents from country}}{\text{Total number of respondents}}$$

For the first term, annual stillbirths were used when the analysis pertained to a stillbirth population (e.g. investigations following stillbirth, provision of autopsy counselling to bereaved parents), and

annual births were used when the analysis pertained to a pregnancy population (e.g. risk factors for stillbirth, interventions for stillbirth prevention). Countries that contributed only a few responses (e.g., <20) were omitted from the weighted analysis because the weights derived from such small numbers were imprecise. This meant that, in total, depending on the survey question, 1-5% of responses were omitted. Sensitivity analyses on the unweighted results showed that omission of responses from countries that contributed only a few responses made no material difference to the results. Quantitative analyses were performed using SPSS (Version 22, IBM, NY, USA) and Microsoft Excel. Quantitative data are reported descriptively only. Here we report descriptive statistics only for a series of closed questions asking whether respondents had to meet any additional costs at the time of delivery. In addition to these data, respondents were asked “Did you have any other sources of support? How were these sources helpful or unhelpful?” and “Is there anything you would like to tell us about the financial costs, impacts or effects of having a stillborn baby?” These free-text responses were converted into English using Google Translate software. The sources of support for bereaved parents (if any) were categorized using thematic analysis by two investigators (JB, WT). The costs (financial and emotional), the impact the stillbirth (or neonatal death?) had on them and whether the support was helpful or unhelpful were categorized in the same manner. Both researchers met regularly to ensure robustness of the analysis, findings were not compared until both researchers’ data sets were complete to avoid bias. Themes were ordered in terms of number of responses with those receiving most responses ranking highest. Where costs were reported by parents in the free text section, the value of the cost, country and currency were recorded and converted to US dollars in 2013 prices for comparison.

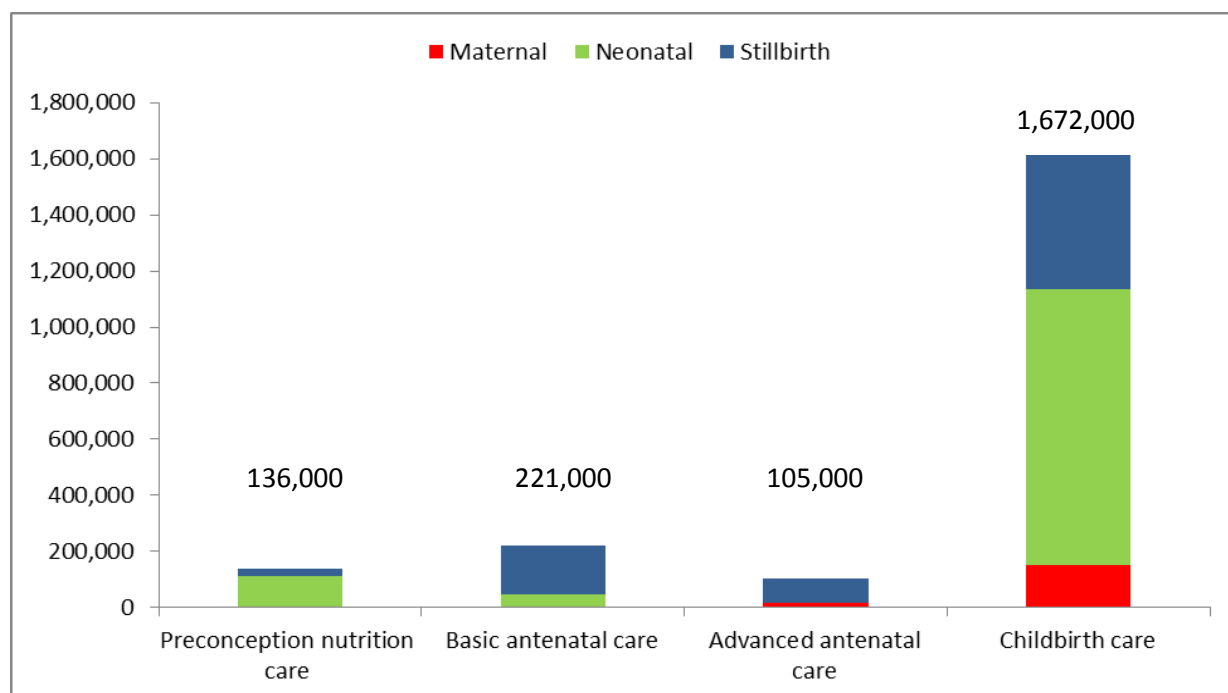
Results

Data from modelled scenario and LiST analysis demonstrating the impact and cost of 90% coverage for quality antenatal and intrapartum care

Table 1: Impact and costs of scale up of intervention packages

Intervention packages	Number of deaths averted				Total additional cost (US\$)	Cost per death averted (US\$)			
	Stillbirths	Neonatal deaths	Maternal deaths	Combined deaths: maternal, neonatal and stillbirths		Stillbirth	Neonatal death	Maternal death	Stillbirth, maternal or neonatal death
Preconception Nutrition Care	22000	114000		136000	1878200000	85373	16475		13810
Basic antenatal care	175000	45000	500	221000	183140000	1047	4070	3662800	830
Advanced antenatal care	90000		15000	105000	220185000	2447		14679	2097
Childbirth care	535000	986000	151000	1672000	2291922000	4284	2325	15179	1370
Total for all intervention packages	823000	1145000	166000	2134000	4573447000	5557	3994	27551	2143

Figure 1 : Number of lives saved at 90% coverage by package.



Critical evaluation of approaches to capture costs of stillbirth

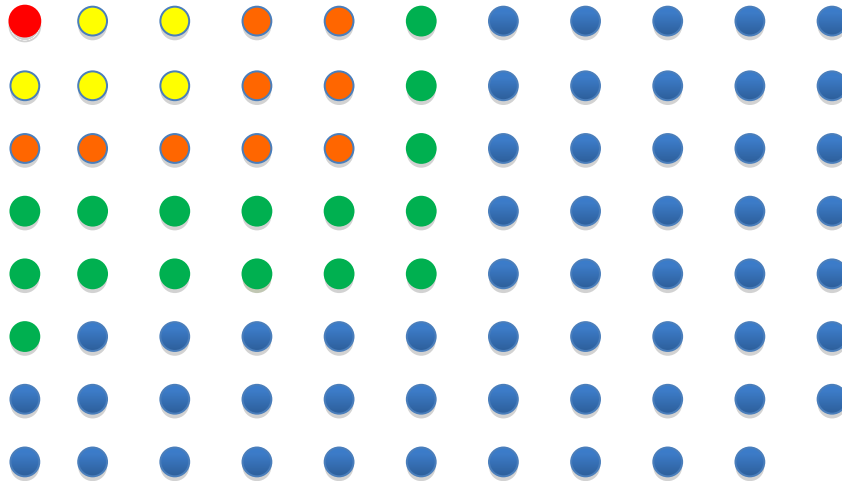
The death of a baby to stillbirth can have negative health effects on multiple individuals, including the mother, other prospective parents, siblings, close relatives, clinical staff and the stillborn baby. The magnitude of the total health loss associated with stillbirth is substantially affected if the stillbirth is counted as a loss in its own right (i.e. as a loss to the baby). Policy-makers making use of economic evaluations of interventions to prevent stillbirths have to make the critical decision of whether and how to count this loss.

Economic evaluations of interventions to reduce neonatal mortality typically present results to policy makers based on the time-discounted life expectancy of surviving infants.¹⁴ Consistency suggests that stillborn babies should be treated in the same way.^{15, 16}

The use of QALYs in NICE guidance and earlier iterations of DALYs apply discounting techniques to accommodate time-discounting of future benefits, giving, e.g. 25 QALYs lost or 32.4 DALYs associated with stillbirth.^{17, 18} The appropriateness of time-discounting of health benefits is the subject of much debate.¹⁹ Without discounting—consistent with the current methodology for the calculation of DALYs for neonatal deaths—stillbirth would be associated with 86 DALYs on account of the loss to the baby. Other approaches to estimating the value of early lives lost have been explored. Jamison et al. suggest that deaths before age 2 should be adjusted according to degree of cognitive development or “acquired life potential (ALP).” With time-discounting this gives DALY values of between 5 and 9. Without time-discounting this would give DALY values of between approximately 14 and 26.

The key point is that a decision about the valuation of the loss to the stillborn baby is required before calculating the value of preventing stillbirth. If the life of a stillborn baby is given value in its own right, discounting or not, the value of the loss of life (in terms of QALYs or DALYs) will be so substantial that it will dwarf the losses to others who are affected (Figure).

Figure 2 - Infographic to demonstrate effect of applying different DALY values to the stillborn baby.



Key

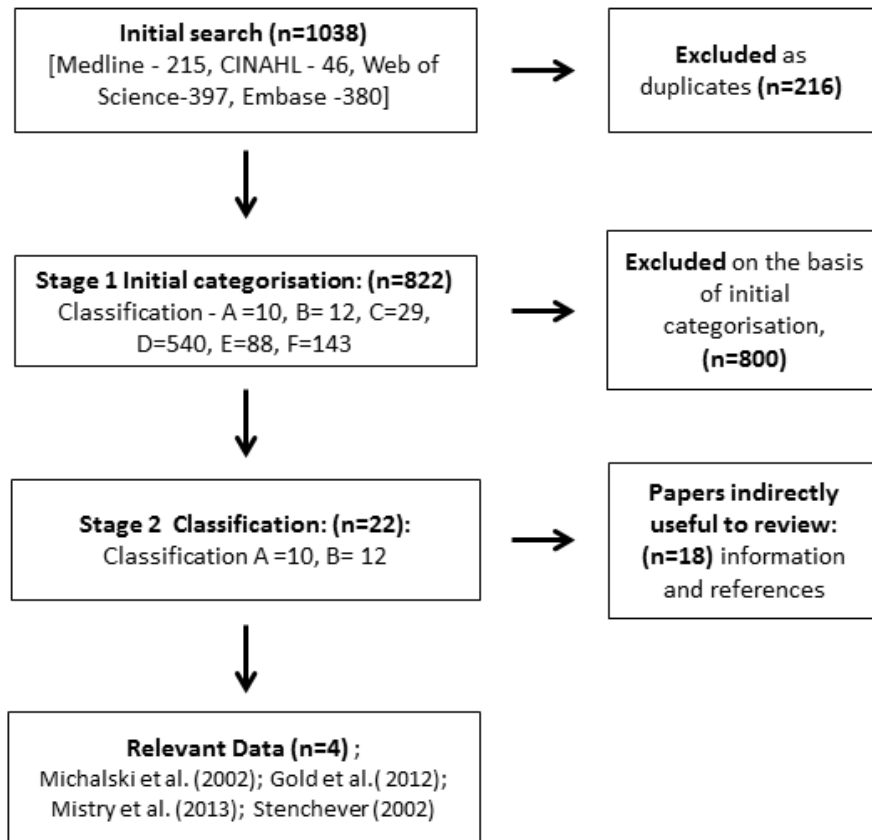
- *Total loss to mother, family, care team, and society*
- *Including fetal loss (ALP and time discounting – antepartum)*
- *Including fetal loss (ALP only – antepartum)*
- *Including fetal loss (time discounting only)*
- *Including fetal loss (no discounting)*

Output of search strategy for economic costs of stillbirth

The updated searches did not identify any new papers since the prior search in 2013.¹ Consequently all papers categorised as most relevant to the review (Group A) had already been cited in the review by Mistry et al (2013).²⁰⁻²⁴ All papers identified and coded as having possible relevant (Group B) were not on closer inspection deemed to yield information that would be useful to the review. Therefore, three papers, all from HICs, that reported direct costs of care after stillbirth between 2000-2012 were included in the analysis.^{1, 21, 23}

Search Summary and PRISMA diagram – Economic Costs of Stillbirth

Code	Definition	Code after scan of title and abstract
A	The study report primary or secondary research on estimating the resource use or costs associated with still birth	10
B	The study reports resource use in care pathways for women who have experienced stillbirth	12
C	Study may have useful information but does not fall into A or B	29
D	The study does not have any relevance to cost and resource use of stillbirth	540
E	Insufficient information – typically and abstract or just a citation on the database with no existing paper	88
F	Not related to Stillbirth in humans	143



Output of search strategy for economic costs in subsequent pregnancy

Initial database searches did not identify any relevant studies. Using the PEARL approach two articles were identified that provided definitive care pathways for the management of pregnancy following stillbirth.^{3, 25} A single article asked a group of obstetricians how they would manage future pregnancy in women who have a history of stillbirth.²⁶ The last identified article asks women who have suffered loss through stillbirth how they would like to be managed in future pregnancies.²⁷ Two other relevant articles were identified, one was a narrative reviews to evaluate interventions in subsequent pregnancy, which found little or no evidence base to support specific interventions.²⁸ One older study identified the increase detection rate of abnormalities in antenatal testing and in subsequent pregnancies, however, it does not recommend a specific management pathway.²⁹

Output of search strategy for psychological and social impact on parents

The search strategy identified 2,619 abstracts. After removal of duplicates and screening for eligibility 240 were selected for full-text retrieval. Two papers were obtained for interest, one was unavailable (a conference abstract), 18 were removed as duplicates, and 63 papers were removed based on exclusion criteria. Nine papers were excluded for practical reasons (needing translation not available to the team). A total of 144 were included and findings extracted for analysis, 129 from HICs and 15 from LMICs. The manuscripts are summarised in the following table:

Search Summary and PRISMA diagram – Psychological Impact on Parents

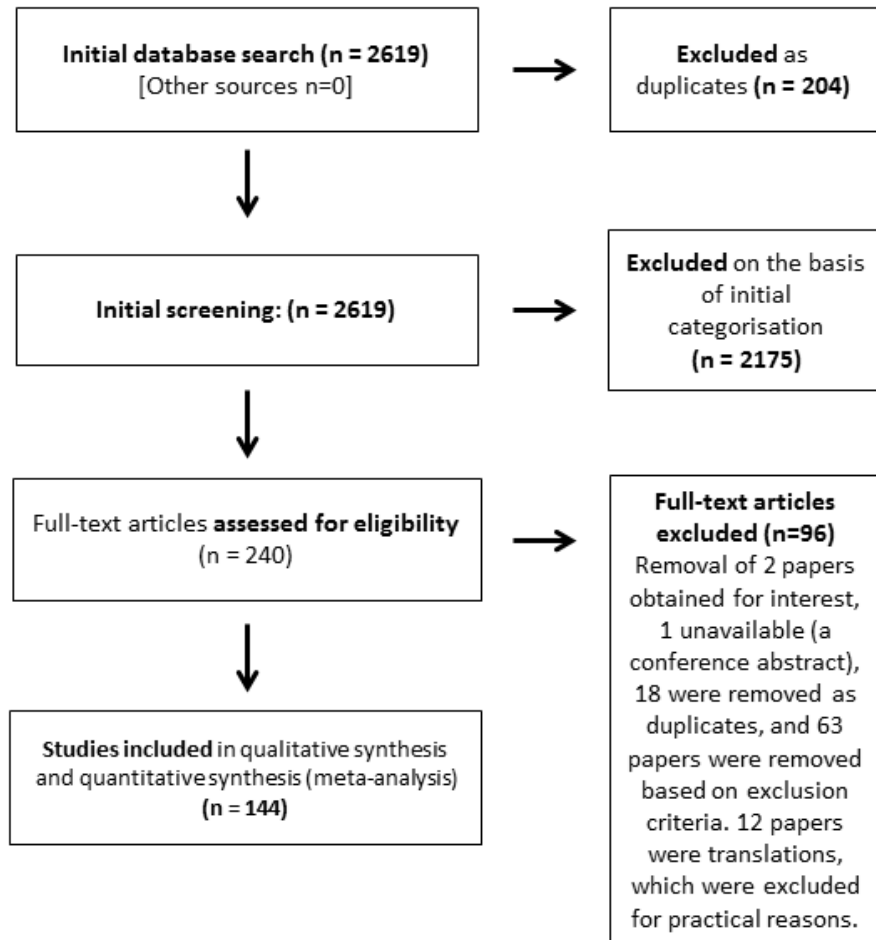


Table 2 – Studies included in systematic review of the psychological and social impact of stillbirth.

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Asia	Sun ³⁰	2014	Taiwan (UMIC)	Bereaved married mothers & fathers	Experiences after stillbirth Seeing or not seeing the infant	Descriptive phenomenological approach In depth interviews	Giorgis method	24	Asian	NS	22, 28, 30, 26, 25, 23, 33, 31, 28, 35, 30, 24
Asia	Tseng ³¹	2014	Taiwan (UMIC)	Bereaved married mothers	Recovery after stillbirth	In depth individual interview with purpose full samplings	Inductive analytical, phenomenological approach	21	Asian	NS	20-37
North America	Gold (Abstract)	2014	USA (HIC)	Bereaved mothers	Mental health outcomes after stillbirth	Longitudinal survey	Quantitative	378 bereaved mothers 232 live birth mother	19% African-American in bereaved group	NS	NS
North America	Huberty ³²	2014	USA (HIC)	Bereaved mothers	Physical exercise after stillbirth	Semi-structured interviews	Thematic analysis	24	Caucasian-91.6%%	6.33 ± 3.06 month	20-38
Africa	Sisay ³³	2014	Ethiopia (LIC)	Grandmothers, mothers – married & unmarried	Attitudes & values around stillbirth & neonatal death	Focus groups	Framework analysis guided by phenomenological approach	63 grandmother s 74 women 70 unmarried girls	African	NS	28 +
Europe	Ryninks ³⁴	2014	UK (HIC)	Bereaved mothers	Experience of contact with stillborn infant	In depth interviews	Interpretive phenomenological analysis-IPA	21	White 85.1%	3/12 after stillbirth	24+
Middle East	Mehran ³⁵	2013	Iran (UMIC)	Mothers	Perinatal loss and maternal-fetal attachment behaviours	Questionnaire, with convenience sampling MFA scale	Quantitative	100 pregnant women with or without history of perinatal loss	Arab	NS	NS
Europe	Avelin ³⁶	2013	Sweden (HIC)	Bereaved mothers & fathers	Grief and relationships after perinatal loss	Postal questionnaire – closed & open questions	Quantitative & content analysis	55 - 33 mothers 22 fathers	NS	NS	22- 40
Europe	Cacciatore ³⁷	2013	Sweden (HIC)	Bereaved fathers	Fathers' experience after fetal loss	Questionnaire – open and closed	Quantitative & content analysis	131	NS	Majority (n=99) > 2 yrs	22+

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Europe	Erlandsson ³⁸	2013	Sweden (HIC)	Bereaved mothers	Seeing & holding a stillborn baby	Online questionnaire	Quantitative	840	NS	0-55 yrs	22-42
Europe	Lindgren ³⁹	2013	Sweden (HIC)	Bereaved mothers	Experiences after stillbirth	In depth interviews	Content analysis	23	NS	5 weeks – 6 yrs	NS
North America	Welborn ⁴⁰	2012	USA (HIC)	Bereaved mothers	Expressing & donating milk after perinatal loss	Semi-structured interviews	Colaizzi's phenomenological methodology	21	NS	NS	NS
North America	Alves ⁴¹	2012	USA (HIC)	Bereaved mother	Meaning following perinatal loss	Constructivist grief therapy	Innovative moments coding system	1	African - American	6 mths	28
Australasia	Barr ⁴²	2012	Australia (HIC)	Bereaved mothers & fathers	Emotion & grief after perinatal loss	Self-reported questionnaire	Quantitative	126 63 couples	English-Australian 76%	1 mth	20+
Europe	Murphy ⁴³	2012	UK (HIC)	Bereaved mothers & fathers	Stillbirth, stigma and moral identity	In-depth interviews	Grounded theory analysis	32 10 couples 12 mothers	Caucasian	6mths-19yrs	24+
Europe	Heazell ⁴⁴	2012	UK (HIC)	Bereaved mothers & fathers	Consent process for perinatal post-mortem after stillbirth	Online survey – open and closed questions	Quantitative	460	Caucasian 95%	2000 +	24+
Europe	Gravensteen ⁴⁵	2012	Norway (HIC)	Bereaved mothers	Long term of stillbirth on depression & QoL	Case/control Questionnaire QLI, CES-D, GHQ-20	Quantitative	106 262 live birth mother controls	NS	NS	23+ or birthweight > 500 grams
Asia	Sutan ⁴⁶	2012	Malaysia (UMIC)	Bereaved mothers	Psychosocial impact of stillbirth on Muslim women	Focus groups and unstructured interviews	Open coding, thematic analysis	16	Asian	NS	22+ or birthweight > 500 grams
North America	Kelley ⁴⁷	2012	USA (HIC)	Bereaved mothers & fathers	Parents & physicians experiences of stillbirth	Focus groups	Thematic discourse analysis	18 mothers 2 fathers	NS	NS	NS

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Europe	Kersting ⁴⁸	2011	Germany (HIC)	Bereaved mothers	Experiences after fetal loss and cognitive behavioural therapy	RCT Questionnaire	Quantitative	83	NS	NS	2-40
Europe	Aho ⁴⁹	2011	Finland (HIC)	Bereaved Fathers	Experiences after fetal loss and intervention	RCT Questionnaire	Quantitative	103 bereaved fathers - 62 control- 41	NS	6 mths	20 (or birth weight> 500 grams) -41
Europe	Erlandsson ⁵⁰	2011	Sweden (HIC)	Bereaved mothers	Mothers' experiences	Online questionnaire	Qualitative content analysis	515	NS	0-41 yrs Av – 5 yrs	22+
Europe	Avelin ⁵¹	2011	Sweden (HIC)	Bereaved mothers & fathers	Experiences after stillbirth and sibling support	Focus groups	Content analysis	27	NS	1-22 yrs Av – 6 yrs	22+
Europe	Malm ⁵²	2011	Sweden (HIC)	Bereaved mothers	Experiences after stillbirth	In-depth interviews	Content analysis using inductive method	21	NS	1mth-80mths	30-42
Asia	Gausia ⁵³	2011	Bangladesh (LIC)	Mothers	Experiences after perinatal loss in LIC	Questionnaire interviews	Quantitative	476 122 - bereaved m others	Asian	NS	NS
North America	Lang ⁵⁴	2011	Canada (HIC)	Bereaved mothers & father	Disenfranchise d grief	Interviews	Content analysis	52- 26 couples	English-Canadian 13% or Other-French, Greek, Italian, Lebanese, Chinese	2mths, 6 mths & 13 mths	9 losses < 20
Europe	Erlandsson ⁵⁵	2011	Sweden (HIC)	Bereaved mothers & fathers	Support, stillbirth & grief	Questionnaire	Quantitative	55 33 mothers 22 fathers	NS	3mths, 1yr and 2 yr after stillbirth	22+
Asia	Yamazaki ⁵⁶	2010	Japan (HIC)	Bereaved mothers	Experiences after stillbirth	Interviews	Grounded theory, inductive analysis	17	Asian	> 1yr	28+
Europe	Vidal ⁵⁷	2010	Portugal (HIC)	NA	Pregnancy after perinatal loss	NA	NA	NA	NA	NA	NA

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Europe	Radestad ⁵⁸	2010	Sweden (HIC)	Bereaved mothers	Advice for pregnancy after stillbirth	Questionnaire	Quantitative	31	Nordic	1 yr	22+
Europe	Erlandsson ⁵⁹	2010	Sweden (HIC)	16 mothers and 9 fathers to siblings of stillborn child (surviving twins excluded) 19 siblings, age range 2-12, mean = 7	Siblings farewell to a stillborn baby	Questionnaire	Quantitative	44	Nordic	3mths & 1 yr	22+
Asia	Sutan ⁶⁰	2010	Malaysia (UMIC)	Bereaved mothers	Psychosocial impact of stillbirth	Self-administered questionnaire	Quantitative	62	Asian -	6 wks- 1 yr	NS
Asia	Fottrell ⁶¹	2010	Benin (LIC)	Mothers after obstetric complications	Psychological distress after obstetric complications	Interview Questionnaire	Quantitative	694 near miss & perinatal death = 64	Asian	2wks, 6 & 12 mths	NS
North America	Forhan ⁶²	2010	Canada (HIC)	Bereaved mother	Family's' journey after perinatal loss	Autoethanography	NS	1	NS	Immediately after loss	37
Europe	Turton ⁶³	2009	UK (HIC)	Mothers	Children subsequent to stillbirth	Interviews Questionnaires Observational test	Quantitative	103 bereaved mothers with subsequent children aged 6-8 yrs - 62	Caucasian 65.7%	NS	NS
North America	Armstrong ⁶⁴	2009	USA (HIC)	Bereaved mothers & fathers	Psychological distress after the birth of a health child after perinatal loss	Interview Questionnaires - CES-D, IES	Quantitative	72 - 36 couples	Caucasian 95.5%	3 rd trimester, 3-6mths & 6-8mths postpartum	NS
Europe	Radestad ⁶⁵	2009	Sweden (HIC)	Bereaved mothers	Long-term outcomes & holding their stillborn baby	Questionnaire. STAI-S, STAI-T, CES-D	Quantitative	309	NS	NS	28-42

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Cacciatore ⁶⁶	2009	USA (HIC)	Bereaved mothers	Social support and maternal anxiety & depression	Questionnaire - HSCL	Quantitative	769	Caucasian – 88.6%	18 mths	NS
Europe	Turton ⁶⁷	2009	UK (HIC)	Mothers	Long term sequelae of stillbirth	Case-control Structured clinical interview for DSM IV	Quantitative	103 - 52 bereaved mothers	Caucasian - 65.4%	7 yrs after pregnancy subsequent to stillbirth	18 +
Europe	Surkan	2009	Sweden (HIC)	Bereaved mothers	Social support	Postal questionnaire and CES-D	Quantitative	314	Nordic	3 yrs	28+
Africa	Adeyemi ⁶⁸	2008	Nigeria (LIC)	Mothers	Depression after perinatal loss	Interview Questionnaire – HAD, EDPS	Quantitative	108 -54 bereaved mothers, 54 controls	NS	Immediately after loss	NS
North America, Europe	Cacciatore ⁶⁹	2008	Canada, USA, UK (HIC)	Bereaved mothers	Contact with stillborn babies & maternal depression & anxiety	Questionnaire - HSCL	Quantitative	2,900	Caucasian – 90.1%	< 1yr – 3+ yrs	NS
Europe	Surkan ⁷⁰	2008	Sweden (HIC)	Bereaved mothers	Events after stillbirth in relation to depression	Questionnaire CES-d	Quantitative	380	NS	In 1991	28+

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Barr ⁷¹	2008	USA (HIC)	Bereaved mothers	Fear of grief & death in bereaved mothers	Online questionnaire – PGS -33, MFODS	Quantitative	400	European American (n = 288, 72%), African American (n = 6, 1.5 %), Native American (10, = 2.5 %), Asian American (n=3, 0.8 %), Hispanic(n = 13, 3.3 %), and other(non-American) (n=80, 20 %)	0-343 mths average = 8	NS
Europe	Pidgeon ⁷²	2007	UK (HIC)	Bereaved father	Life after stillbirth	Narrative- N/A	N/A	1	NS	NS	NS
North America	Cacciatore ⁷³	2007	USA (HIC)	Bereaved mothers	Mothers' experience after stillbirth	Qualitative and open narrative postal questionnaire	Qualitative, phenomenological approach	47	38 European Americans - 3 African Americans - 3 Latino -2 Other -1	1- 10yrs	20-37
Europe	Turton ⁷⁴	2006	UK (HIC)	Mothers & fathers	Impact of stillbirth on fathers in subsequent pregnancy	Interviews Questionnaire – BDI, EPDS, SSDI, PTSD-I, GRIMS	Quantitative	200-37 - controls 32 bereaved couples in subsequent pregnancy	Caucasian 72.4% African 11.8% Asian 10.5%	11-44 mths average – 18.8	20-41

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	O'Leary ⁷⁵	2006	USA (HIC)	Bereaved fathers	Fathers' perspectives after stillbirth	Interviews Descriptive phenomenology	Giorgis method of analysis	10	NS	Within 1 yr	NS
Australasia	Barr ⁷⁶	2006	Australia (HIC)	Bereaved mothers & fathers	Grief & subsequent pregnancy	Semi-structured interviews and PGS questionnaire	Quantitative	126 couples-31 bereaved by stillbirth	English-Australian – 76%	1mth & 13mth FU	20+
Europe	Saflund ⁷⁷	2006	Sweden (HIC)	Bereaved mothers & fathers	Experiences after stillbirth	Questionnaire and Well-Being Questionnaire	Quantitative	55 mothers 33 fathers	Nordic	3 mths	22-43
North America	Lang ⁷⁸	2004	Canada (HIC)	Bereaved mothers & fathers	Health in bereaved parents	Questionnaire – Land & Goulet hardness scale, PGS, support behaviours inventory, family adaptability & cohesion evaluation scale, ENRICH marital satisfaction scale	Quantitative	220 couples	English Canadians – 10% Greek, Italian, Lebanese, Chinese Canadians – 33.3%	2, 6 13 mths	13-40
North America	Armstrong ⁷⁹	2004	USA (HIC)	Bereaved mother & fathers in subsequent pregnancy	Perinatal loss & subsequent pregnancy	Cross-sectional survey – IES, CES-D, PAI	Quantitative	80 – 40 couples	Caucasian 93%	NS	Av – 22.6
North America	Cote-Arsenault ⁸⁰	2004	USA (HIC)	Bereaved mothers & fathers	Support groups & pregnancy loss	Observation of support groups, individual interviews, postal surveys	Quantitative & qualitative	26 –support group 23- women 3- men 12- interviews 130 – postal surveys	90% white, 10% minorities (mainly Pacific Islanders)	NS	NS
Europe	Saflund ⁸¹	2004	Sweden (HIC)	Bereaved mothers & fathers	Role of care givers after stillbirth	Interviews	Qualitative content analysis	57	NS	4-6 yrs	28+

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Europe	Avelin ⁸²	2014	Sweden (HIC)	13 - 17 year old bereaved adolescent half-siblings to stillborn child	Half-siblings & stillbirth	Interviews	Content analysis	13	NS	NS	NS
North America	Fenstermacher ⁸³	2014	USA (HIC)	Bereaved mothers	Experience of perinatal loss in Black adolescents	Interview- face to face or phone	Qualitative – constant comparative	19	African-American	NS	9-32 Av- 19.8
Europe	Radestad ⁸⁴	2014	Sweden (HIC)	Bereaved mothers	Mothers' experiences	In-depth interviews	Qualitative content analysis with inductive approach	26	NS	<1yr- 6 yrs	28+
North America	O'Leary ⁸⁵	2013	USA (HIC)	Bereaved mothers & fathers & subsequent siblings	Contact with the baby after stillbirth	Interviews	Secondary thematic analysis	9 - elderly bereaved mothers & fathers 7- subsequent siblings	NS	50-70 yrs	NS
Europe	Downe ⁸⁶	2013	UK (HIC)	Bereaved mothers & fathers	Experience in UK hospitals	Qualitative in-depth interviews (face-to-face or telephone)	Constant comparative technique from grounded theory	25	NS	1-9 yrs	24-42
Europe	Murphy ⁸⁷	2012	UK (HIC)	Bereaved mothers & fathers	Finding the positive in perinatal loss	In-depth interviews	Grounded theory	32- 10 couples 12 mothers	Caucasian 30/32	6mths- 17 yrs	24+
Europe	Anderson ⁸⁸	2012	Sweden (HIC)	Bereaved mothers & fathers and surviving twins	Bereavement and twins	Interviews	Thematic analysis	8- 4 parents & 4 surviving twins	NS	35 yr	NS
Europe	Nordlund ⁸⁹	2012	Sweden (HIC)	Bereaved mothers	Psychosocial care after perinatal loss	Online questionnaire	Content analysis	213	NS	0-2yrs	22+
Europe	Kerslake ⁹⁰	2012	UK (HIC)	Bereaved mothers	Learning from loss	Narrative-NA	NA	2	Caucasian	NS	40+

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Australasia	Lee ⁹¹	2012	Australia (HIC)	Bereaved mothers	Experiences after pregnancy loss	Online open ended questionnaire	Thematic analysis	14	NS	3-4mths	20-37
Australasia	Warland ⁹²	2011	Australia (HIC)	Bereaved mothers & fathers	Parenting after infant loss	Informal interviews	Thematic analysis	13	NS	4-18yrs	NS
Australasia, North America	O'Leary ⁹³	2011	Australia, USA (HIC)	Bereaved mother, fathers & grandparents	Bereaved parents & grandparents after fetal loss	Interviews	Thematic analysis	32	Caucasian	1-10yrs	NS
Europe	Dyregov ⁹⁴	2011	Norway (HIC)	NS	Sexuality after stillbirth	Questionnaire and interview (10 couples interviewed)	Quantitative & qualitative	285	NS	NS	NS
Asia	Sun ⁹⁵	2011	Taiwan (UMIC)	Bereaved mothers	Motherhood after pregnancy loss	Interviews	Interpretive phenomenological analysis- IPA	6	Asian	2-3.5 yrs	10-37
Europe	Wood ⁹⁶	2011	UK (HIC)	Bereaved mothers	Stressful life events and pregnancy loss	Interviews Questionnaire – HADS, LTE-Q	Quantitative & qualitative- framework analysis	200	NS	NS	NS
North America	Cote-Arsenault ⁹⁷	2011	USA (HIC)	Bereaved mothers in subsequent pregnancy	Pregnancy after perinatal loss	Mixed methods Self-reported questionnaire- PAS	Quantitative Content & thematic	63	Caucasian - 84%	NS	NS
North America	Capitulo ⁹⁸	2010	USA (HIC)	Bereaved mothers & fathers	Measuring perinatal grief	Questionnaire	Quantitative	90-50 bereaved parents, 40 controls	NS	1 yr	NS
Europe	Gaudet ⁹⁹	2010	France (HIC)	Mothers in subsequent pregnancy	Pregnancy after perinatal loss	Online of face to face - questionnaires – HADS, PGS, PSEQ	Quantitative	170-96 – bereaved mothers 74- controls	NS	NS	NS

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Cacciatore ¹⁰⁰	2010	USA (HIC)	Bereaved mothers	Experiences of women & family after stillbirth	Self-administered postal questionnaire - qualitative and open-ended narrative	Thematic analysis	47	NS	<1 year n= 10 1-2 years n= 10 2-5 years n=17 5-10years n=7 >10 years n = 3	40
Asia	Hiruta ¹⁰¹	2009	Japan (HIC)	Bereaved mothers	Grieving processes	Interviews	Thematic analysis	5	Asian	NA	NA
Europe	Radestad ⁶⁵	2009	Sweden (HIC)	Bereaved mothers	Holding a stillborn baby	Questionnaires	Quantitative	33	NS	3mths	22+
North America	Cacciatore ¹⁰²	2008	USA (HIC)	16 married or cohabiting heterosexual couples + 56 conference attendees	Stillbirth & the couple	Questionnaire, Discussion Group, Narrative responses submitted in writing	Thematic analysis, Constant comparison method	87	NS	NS	NS
North America	Cote-Arsenault ¹⁰³	2007	USA (HIC)	Bereaved mothers in subsequent pregnancy	Pregnancy following perinatal loss	Qualitative study of pregnancy calendar entries and field notes.	Thematic analysis	69	Caucasian 88.4%	NS	NS
North America	Kavanaugh ¹⁰⁴	2004	USA (HIC)	Bereaved mothers & fathers	Social support & perinatal loss	Secondary analysis. Open-ended interview (5 mothers, 3 fathers) Open-ended interviews (17 mothers, 6 fathers)	Colaizzi's approach, Vaux's theory. Concept analysis/thematic analysis	31 - 22 Mothers 9 Fathers	NS	4-15	16-23
Europe	McCreight ¹⁰⁵	2004	UK (HIC)	Bereaved fathers	Males perspective of pregnancy loss	Observations of self-help groups & semi-structured interviews	?Thematic analysis	14	NS	2mths-20yrs	8-40
Asia	Hsu ¹⁰⁶	2004	Taiwan (UMIC)	Bereaved mothers	Interpretation s of stillbirth	Interviews – interpretive ethnographic	Thematic analysis	20	Asian	Within 1 yr	20+
North America	Pector ¹⁰⁷	2004	USA, Canada (HIC)	Bereaved mothers & fathers	Bereavement in multiple-birth	Online survey	Quantitative & qualitative – grounded theory approach	70	NS	1980-2001	NS

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Kavanaugh ¹⁰⁸	2005	USA (HIC)	Bereaved mothers & fathers	Perinatal loss in low income African Americans	Interviews	Qualitative – adapted from Colaizzi	23-17 mothers & 6 partners	African-Americans	NS	17-37
Australasia	St John ¹⁰⁹	2006	Australia (HIC)	Bereaved mothers	Experience of perinatal loss	Unstructured interviews	Content analysis	3	NS	NS	NS
North America	Schiff ¹¹⁰	2006	USA (HIC)	Women who were hospitalised postpartum for a suicide attempt	Risk of suicide and perinatal loss	Case- control note review	Quantitative	520 women & 2204 controls	Caucasian-75%	NS	NS
North America	Cote-Arsenault ¹¹¹	2006	USA (HIC)	Bereaved mothers in subsequent pregnancy	Experiences after fetal loss	Pregnancy calendars, Qualitative descriptive design, complete quant. instruments, field notes from researchers	Thematic analysis and content analysis	82	Caucasian 86.7%	3.5-40 weeks	NS
North America	Cote-Arsenault ¹¹²	2007	USA (HIC)	Bereaved mothers	Pregnancy after perinatal loss	Questionnaire – SiL, MTI, MAACL-R, PAS, WCCL-R	Quantitative	82	Caucasian = 88%	Av – 2.3 yrs	Av – 11.1
North America	Cote-Arsenault ¹¹³	2003	USA (HIC)	Pregnant women 17-28 weeks	Anxiety & perinatal loss	Questionnaire- PAS, LOT, SSA scale	Quantitative	160 women who were - 96 multigravid with no history of loss and 74 women with a history of one or two losses.	Caucasian – 91%	1-12yrs Av 2.93	Av – 10.38

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Hazen ¹¹⁴	2003	USA (HIC)	Bereaved mothers	Disenfranchised grief	Interviews	Thematic analysis	14	Caucasian- 12 African-American - 2	1965-199	NS
Asia	Hsu ¹¹⁵	2002	Taiwan (UMIC)	Bereaved mothers	Adaption to stillbirth	Interviews-interpretive ethnographic approach	Qualitative according to Agar	20	Asian	Within 2 yrs	NS
Europe	Kitson ¹¹⁶	2002	Sweden (HIC)	Bereaved fathers	Fathers' experience after stillbirth	Interviews	Thematic analysis	11	NA	NA	32-42
Europe	Radestad ¹¹⁷	2001	Sweden (HIC)	Mothers	Long term effects of stillbirth	Questionnaire	Quantitative	759 314- bereaved mothers, 322 -controls	NA	NA	
North America	Sanchez ¹¹⁸	2001	Sweden (HIC)	Bereaved mothers	Support after perinatal loss	In-depth semi-structured interviews	Qualitative	12	NS	1992-1995	20+
North America	Armstrong ¹¹⁹	2001	USA (HIC)	Bereaved fathers with partner currently pregnant	Fathers' experiences of pregnancy after loss	Phenomenological. Unstructured in-depth interviews	Thematic analysis	4	3Caucasian, 1 Black Jamaica	< 2yrs	12-20
Europe	Sansoni ¹²⁰	2001	Italy (HIC)	Bereaved parents	Grief after perinatal loss	Questionnaire – HGRC, BDI-II	Quantitative	NA	NA	NA	NA
North America	Cote-Arsenault ¹²¹	2000	USA (HIC)	Bereaved mothers in subsequent pregnancy	Pregnancy after perinatal loss	Qualitative inquiry, focus group or interview (both using interview guide)	Thematic analysis	13	Caucasian = 11, Asian/Pacific Islander = 1, Hispanic = 1	NS	8-37
North America	Grout ¹²²	2000	USA (HIC)	7 Bereaved families: 3 couples, 1 father, 3 mothers	Replacement child after perinatal loss	Interviews –open ended	Grounded theory approach, constant comparative method	10	Caucasian	2-10yrs	NS

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Schreiber ¹²³	2000	Canada (HIC)	Bereaved mothers & fathers	Experiences after perinatal loss	Interviews- semi-structured	Qualitative	22 - 16 women 6 men	NS	NS	20+
Australasia	Vance ¹²⁴	2002	Australia (HIC)	Bereaved mothers & fathers	Couple distress after perinatal loss	Interviews	NS	138	NS	2, 8, 15 & 30 mths	NS
Europe	Doug ¹²⁵	2010	UK (HIC)	Bereaved fathers	PTSD & perinatal loss	Self-completion questionnaires, validated tools to screen and diagnose PTSD, depression and anxiety.	Quantitative	150	NS	4 days & 4 wks post delivery	NS
Australasia	Swanson ¹²⁶	2002	Australia (HIC)	Mothers where 1 twin or higher multiple died	Multiple pregnancies and perinatal loss	Interviews, BDI PGS(Short Version), Focus Groups	Quantitative & thematic analysis	66	Caucasian	0-1 year = 3, 2-5y = 8, 6-10y = 22, 11-15y = 19, 16-20y = 12, 21-41y = 2	NS
Africa	Van der Sijpt ¹²⁷	2014	Cameroon (LMIC)	NS	Pregnancy loss in Cameroon	Observation and discursive strategies	NS	NS	Cameroon - Gbigbil	NS	NS
Europe	Christiansen ¹²⁸	2013	Denmark (HIC)	Bereaved mothers & fathers	PTSD & perinatal loss	Questionnaire package. Harvard Trauma Questionnaire, CSQ, Crisis Support Scale, Revised Adult Attachment Scale	Quantitative	634	NS	1.2mths- 18yrs Av – 3.4 yrs	22+
Europe	Breines ¹²⁹	2013	Norway (HIC)	Bereaved mothers	Grief & anxiety after perinatal loss	Questionnaire	Quantitative	2,753	NA	NA	NA

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America & NS	Gold ¹³⁰	2012	USA(HIC) & NS	Bereaved mothers	Internet message boards for pregnancy loss	Online survey including one open-ended question	Quantitative & summary descriptive statistics	1,006	Caucasian	NS	NS
Europe	Blackmore ¹³¹	2011	UK (HIC)	Bereaved mothers in subsequent pregnancy	Previous loss & depression	Questionnaire	Quantitative	13,133	NS	NS	NS
North America	Hutti ²⁰	2011	USA (HIC)	Bereaved mothers	Pregnancy following perinatal loss	Longitudinal cohort study. Telephone interview. CES-D, Spielberger State-Trait Anxiety Scale, Pregnancy Outcome Questionnaire, IES, Maternal Attitude Questionnaire, also healthcare utilisation	Quantitative	32	African-American - 2.8% White - 93.1% Hispanic/Latino - 2.8% Asian - 1.4%	NS	NS
North America	Cowchock ¹³²	2010	USA (HIC)	Bereaved mothers	Religious beliefs and perinatal loss	Religious questionnaire, PGS	Quantitative	110	NS	4-6 weeks & 1 yr	NS
North America	Gold ¹³³	2010	USA (HIC)	Bereaved mothers & fathers	Relationships after perinatal loss	Data from National Survey of Family Growth	Quantitative	7,770	NS	NS	20+
Europe	Luczak ¹³⁴	2010	Poland (HIC)	Bereaved mothers	Early & late effects of pregnancy loss	NA	NA	NA	NA	NA	NA
Australasia, North America, Europe	Peel ¹³⁵	2010	Australia, Canada, UK, USA (HIC)	Non-heterosexual bereaved mothers	Pregnancy loss in lesbian & bisexual women	Online survey	Quantitative & thematic analysis	60	NS	NS	24+

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
South America	Couto ¹³⁶	2009	Brazil (UMIC)	Bereaved mothers in subsequent pregnancy	Psychological symptoms in pregnancy after perinatal loss	Interviews, Short Form 36 QoL questionnaire, Depression & Anxiety Scale	Quantitative	120	Caucasian - 73	NS	NS
Africa	Obi ¹³⁷	2009	Nigeria (LMIC)	Bereaved mothers	Depression following pregnancy loss in Nigeria	Questionnaire survey. Zung self-rating Depression Scale	Quantitative	202	African	< 3mths	NS
North America	Price	2008	USA (HIC)	Mothers	Parenting capacity after loss	ECLS-B data, incl. modified CES-D, Nursing Child Assessment Teaching Scale	Quantitative	10,688	NS	NS	NS
Europe	McCreight ¹³⁸	2008	UK (HIC)	Bereaved mothers	Perinatal loss	In-depth interviews	Content & thematic analysis	23	NS	<3 years = 18, >3 years = 2, >5 years = 3	NS
North America	Armstrong ¹³⁹	2007	USA (HIC)	Bereaved mothers & fathers	Psychological symptoms in pregnancy after perinatal loss	Telephone interviews, Impact of the Event Scale, CES-D Scale	Quantitative	36	NS	NS	Av – 22.2

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Barr ¹⁴⁰	2007	USA (HIC)	Bereaved mothers	Emotions & grief	Questionnaire (online or download). Dispositional Envy Scale, Interpersonal Jealousy Scale, Personal Feelings Questionnaire-2, PGS-33	Quantitative	441	European-American - 70.5% African-American- 1.8% Native American- 2.5% Asian-American- 0.7% Hispanic-3.4% Other (Non-Am.)-21.1%	0-343 mths Median – 8mths	NS
Europe	Pantke ¹⁴¹	2006	UK (HIC)	University students whose parents experienced perinatal loss when participant was 5yrs or younger.	Young adults whose parents had experienced pregnancy loss	Parent Bonding Instrument. Rosenberg Self-Esteem Scale. Mental Health Index 5	Quantitative	77	NS	13-18 yrs	NS
North America	Coleman ¹⁴²	2005	USA (HIC)	Bereaved mothers	Child maltreatment & perinatal loss	Interviews/ Observation	Quantitative	133	NS	NS	NS
Europe	Jind ¹⁴³	2003	Denmark (HIC)	Bereaved mothers & fathers	Parents adjustment to loss	Questionnaire	Quantitative	110	NS	1-4 wks & 1 yr	15-22
North America	Van ¹⁴⁴	2003	USA (HIC)	Mothers	Grief after pregnancy loss	Semi-structured interviews. Grounded theory method.	Constant comparative	20	African-American	< 3yrs Av -2	1 st trimester majority
Europe	Lee ¹⁴⁵	2002	UK (HIC)	1 mother, 1 psychotherapist	Grief in future pregnancy after perinatal loss	Narrative	NS	2	NS	NS	37+

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Franché ¹⁴⁶	2001	Canada (HIC)	Bereaved mothers	Grief in future pregnancy after perinatal loss	Questionnaire-PGS, Depressive Experiences Questionnaire - Self-Criticism Subscale, Abbreviated Dyadic Adjustment Scale	Quantitative analysis	110	NS	< 4 yrs Av – 15.1 mths	4-42 Av – 17.5
North America	Van ¹⁴⁷	2001	USA (HIC)	Bereaved mothers	African-American women after perinatal loss	Individual interviews, open-ended questions	Grounded theory methodology, thematic analysis	10	African-American	Av – 4 yrs	NS
Europe	Wilson ¹⁴⁸	2001	UK (HIC)	8 families (5 couples, 3 mothers) with at least one other child at time of perinatal loss	Support for siblings after perinatal loss	Semi-structured interviews	McLeod's stages, concept analysis	13	NS	< 6 yrs	NS
Europe	Bernazzani ¹⁴⁹	2003	UK (HIC)	Bereaved mothers & sisters	Vulnerability factors for depression	Interviews. Present State Examination, Childhood Experience of Care and Abuse, Adult Life Phase Interview, Pregnancy Birth Ratings, Marital Ratings	Quantitative	198	NS	NS	NS
North America	Hopkins Hutti ¹⁵⁰	2014	USA (HIC)	Bereaved mothers in subsequent pregnancy	Grief in subsequent pregnancy after perinatal loss	Online Pregnancy Outcome Questionnaire, IES, CES-D, Autonomy and Relatedness Inventory, PGIS	Quantitative	227	NS	NS	NS
North America	Varney ¹⁵¹	2014	USA (HIC)	Bereaved mother & father	Perinatal loss	Narrative / Psychotherapist's notes	NS	2	Caucasian	NS	NS

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Shreffler ¹⁵²	2011	USA (HIC)	Bereaved mothers	Distress & Pregnancy loss	Questionnaire	Quantitative	1284	Caucasian 60% Black 15% Hispanic 23% Other 0.02%	0.05 -25.12 yrs Av 11.13yrs	NS
NS	Froen ¹⁵³	2011	NS	Bereaved mothers & fathers	Why stillbirths matter	Online survey	Quantitative	3617	NS	NS	22+
North America	Jaffe ¹⁵⁴	2011	USA (HIC)	Psychotherapist	Experience of stillbirth	Narrative	NA	1	NS	NS	NS
Europe	Reid ¹⁵⁵	2007	UK (HIC)	Bereaved mothers & fathers	Pregnancy loss & subsequent pregnancy	Narrative	NA	4	NS	NS	19-40
Europe	Hughes ¹⁵⁶	2006	UK (HIC)	Bereaved mothers	Infant disorganisation after perinatal loss	Questionnaire, Adult Attachment Interview, EPDS, Spielberger State-Trait Inventory, PTSD-I Interview, Strange Situation procedure	Quantitative	31	NS	NS	18+
Europe	Turton ¹⁵⁷	2004	UK (HIC)	Bereaved mothers in subsequent pregnancy	PTSD & stillbirth	Cohort study. Demographic info questionnaire, PTSD-I Interview, Adult Attachment Interview, Strange Situation assessment of infant security.	Quantitative	60	NS	NS	NS
Europe	Hughes ¹⁵⁸	2001	UK (HIC)	Children subsequent to stillbirth	Infants born subsequent to stillbirth	Detailed interview. Demographic questionnaire. AAI, EPDS, SSTI, Beck Depression Inventory, Strange Situation test	Quantitative	53 (+ 53 control infants)	Caucasian - 34 (64%), Afro-Caribbean - 6 (11%), Indian/Pakistani - 9 (17%), African - 3 (6%), Chinese - 1 (2%)	11mths-186mths Av- 18mths	<28 weeks -31 (56%) >27 weeks - 24 (44%)

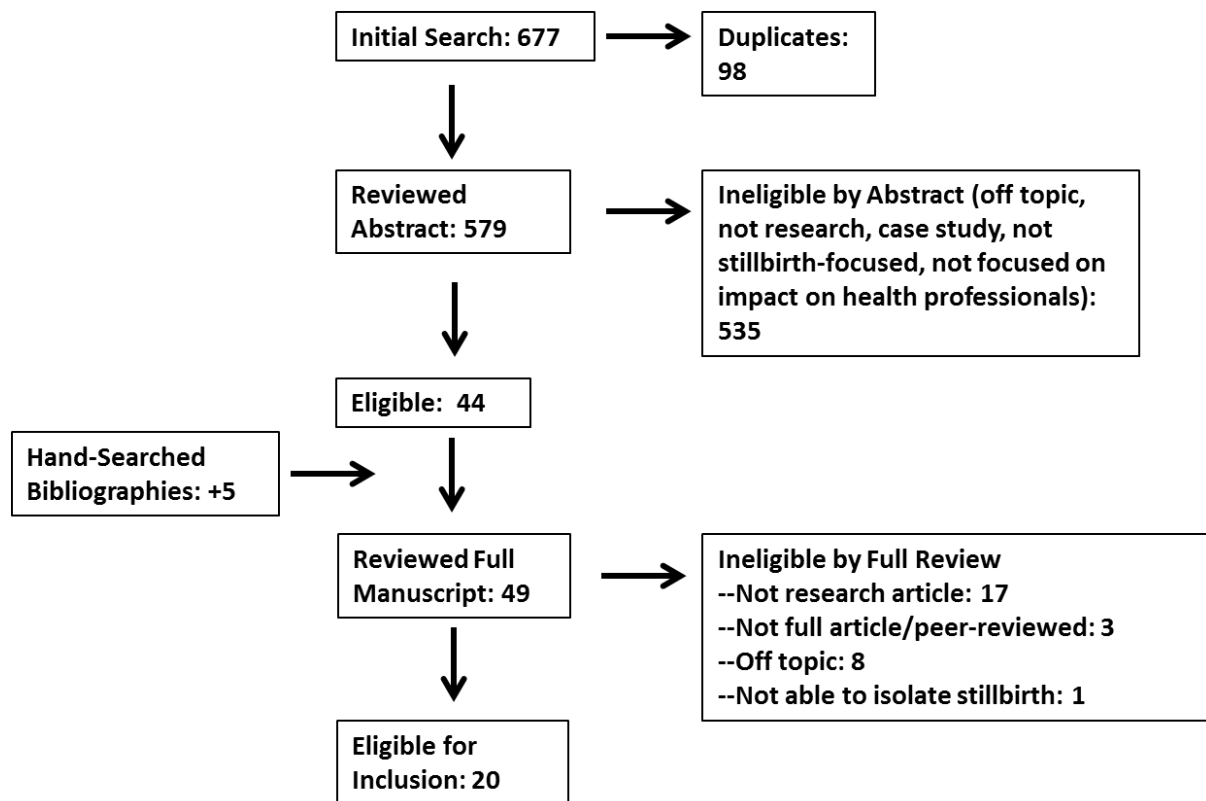
Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
North America	Hogue ¹⁵⁹	2015	USA (HIC)	Bereaved Mothers	Stillbirth & depression	Telephone interview, use of psychosocial instruments. EDS, Spielberger Trait Anxiety Scale, Stressful Life Events Scale	Quantitative	275 (+ 522 controls live-birth)	Caucasian - 45.1% Black – 18.8% Hispanic – 29.9%	6-36 mths	18- > 37
North America	Gold ¹⁶⁰	2014	USA (HIC)	Bereaved mothers	Anxiety & OCD after perinatal loss	GAD-7, MINI-SPIN, PRIME-MD PHQ Panic Module, Obsessive Compulsive Inventory, PHQ-8, MOS-SSS, plus intimate partner violence	Quantitative	377 (+ 232 controls live-birth)	Caucasian – 76% African America -19%	Median – 9mths	NS
North America	Tran ¹⁶¹	2014	USA (HIC)	Bereaved mothers	Smoking & pregnancy loss	Perinatal records extracted from NSW Perinatal Data Collection and NSW Admitted Patient Data Collection	Quantitative	1144	NS	NS	NS
North America	Lacasse ¹⁶²	2014	USA (HIC)	Bereaved mothers & fathers	Psychiatric medication after pregnancy loss	Observational study, online survey of prescribed medication	Quantitative & life table analysis	235	Caucasian – 82.3%	NS	20+
Europe	Newitt ¹⁶³	2014	UK (HIC)	Bereaved mothers & fathers	Spiritual support and perinatal loss	Narrative/chaplain notes	NA	8	NS	NS	NS

Continent	Author	Date	Location	Participants	Topic	Design	Analysis	Sample size	Ethnicity	Time since stillbirth	Gestation at time of stillbirth (weeks)
Europe	Brierley-Jones	2015	UK (HIC)	Bereaved mothers	Stillbirth & stigma	Online questionnaire: Making and Sharing Memories Questionnaire. Free-text responses to open-ended questions. DASS-21, Posttraumatic Stress Symptom Scale.	Thematic & Content analysis	162	Caucasian – 95%	< 10yrs 0.25 - 120mths	20-43
Asia	Takaki ¹⁶⁴	2014	Japan (HIC)	Women undergoing fertility treatment (not all with previous perinatal loss)	Psychological symptoms and fertility treatment	Postal questionnaire. Kessler 6 question Psychological Distress Scale.	Quantitative	635	NS	NS	NS
Europe	Munk-Olsen ¹⁶⁵	2014	Denmark (HIC)	Cases of perinatal loss	Psychiatric disorders after perinatal loss	Population-based cohort study. Data from nationwide population registers	Quantitative	87,687	NS	12mths	NS
North America	Hutti ¹⁶⁶	2015	USA (HIC)	Bereaved mothers in subsequent pregnancy	Subsequent pregnancy after perinatal loss	Cross-sectional online survey. Pregnancy Outcome Questionnaire, IES, CES-D, ARI, PGIS	Quantitative	227	Caucasian – 78% Other – 22%	NS	20+
Europe	Christiansen ¹⁶⁷	2014	Denmark (HIC)	Bereaved mothers & fathers	Bereavement and sex differences after perinatal loss	Cross-sectional study, written questionnaire. HTQ Part IV, Revised Adult Attachment Scale, Coping Styles Questionnaire, Crisis Support Scale	Quantitative	634	NS	1.2 mth – 18yrs Av – 3.4yrs	13-44 Av- 34.5

NS – not specified, N/A – not applicable, NA – not available.

Output of search strategy for psychological impact on professionals

Search Summary and PRISMA diagram – Psychological Impact on Professionals



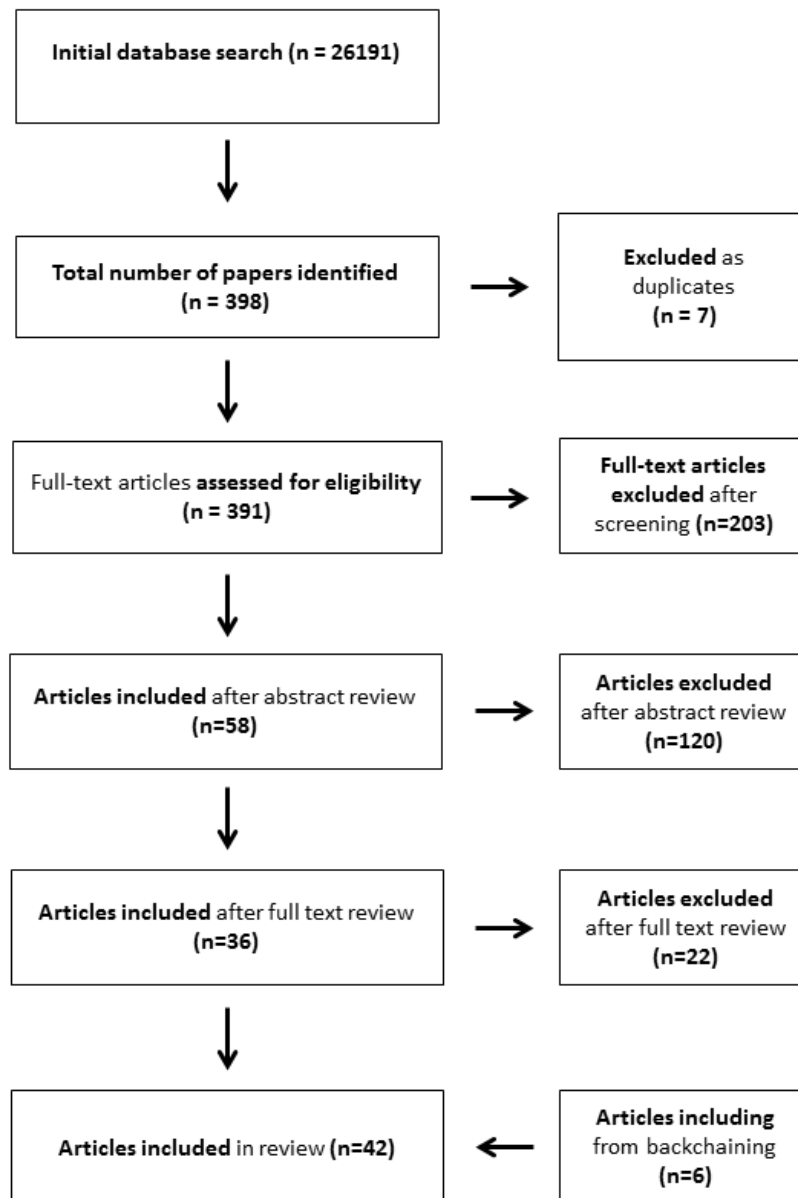
20 studies (10 Qualitative, 6 mixed-methods & 4 Quantitative) met the inclusion criteria of which 19 were from HICs^{47, 168-185} and one was from a mixture of both HICs and LMICs.¹⁸⁶ Eighteen studies were published between 2008-2014^{47, 168-172, 174-181, 183-186} and 2 were published in 2000.^{173, 182} Further details of the included studies are shown the following table:

Table 3 – Studies included in systematic review of psychological impact on professionals

Citation	Year	Country
Ben-Ezra, M., Y. Palgi, et al. (2014). "The impact of perinatal death on obstetrics nurses: A longitudinal and cross-sectional examination." <i>Journal of Perinatal Medicine</i> 42(1): 75-81.	2014	Israel
Clavel, B., C. Dupont, et al. (2013). "[Intervention of psychological and ethical professionals of human science in obstetrical morbidity and mortality conferences]." <i>Journal de Gynecologie, Obstetrique et Biologie de la Reproduction</i> 42(4): 383-392.	2013	France
Farrow, V. A., R. L. Goldenberg, et al. (2013). "Psychological impact of stillbirths on obstetricians." <i>Journal of Maternal-Fetal and Neonatal Medicine</i> 26(8): 748-752.	2013	USA

Gold, K. J., A. L. Kuznia, et al. (2008). "How Physicians Cope with Stillbirth or Neonatal Death: A National Survey of Obstetricians." <i>Obstetrics and Gynecology</i> 112(1): 29-34.	2008	USA
Jonas-Simpson, C., E. McMahon, et al. (2010). "Nurses' experiences of caring for families whose babies were born still or died shortly after birth." <i>International Journal for Human Caring</i> 14(4): 14-21	2010	Canada
Kaunonen, M., M. Tarkka, et al. (2000). "The staff's experience of the death of a child and of supporting the family." <i>International Nursing Review</i> 47(1): 46-52.	2000	Finland
Kelley, M. C. and S. B. Trinidad "Silent loss and the clinical encounter: Parents and physicians experiences of stillbirth - a qualitative analysis." <i>BMC Pregnancy Childbirth</i> 12: 137-137.	2012	USA
Liisa, A. A., T. Marja-Terttu, et al. (2011). "Health care personnel's experiences of a bereavement follow-up intervention for grieving parents." <i>Scandinavian Journal of Caring Sciences</i> 25(2): 373-382.	2011	Finland
McAninch, C. B., S. P. Chauhan, et al. (2008). "Psychologic effects of poor outcome and professional liability actions on physicians." <i>Southern Medical Journal</i> 101(10): 1032-1034.	2008	USA
McCool, W., M. Guidera, et al. (2009). "The pain that binds us: midwives' experiences of loss and adverse outcomes around the world." <i>Health Care for Women International</i> 30(11): 1003-1013.	2009	USA, Asia, South America, Australia, Africa, Europe
McKenna, L. and C. Rolls (2011). "Undergraduate midwifery students' first experiences with stillbirth and neonatal death." <i>Contemporary Nurse</i> 38(1-2): 76-83.	2011	Australia
Nallen K. Neonatal and infancy. Midwives' needs in relation to the provision of bereavement support to parents affected by perinatal death. Part two. <i>MIDIRS Midwifery Digest</i> . 2007;17(1):105-12.	2007	Ireland
Nuzum, D., S. Meaney, et al. (2014). "The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study." <i>BJOG</i> 121(8): 1020-1028.	2014	Ireland
Nuzum, D., S. Meaney, et al. (2014). "The provision of spiritual and pastoral care following stillbirth in Ireland: a mixed methods study." <i>BMJ Support Palliat Care</i> , doi:10.1136/bmjspcare-2013-000533	2014	Ireland
Pastor Montero, S. M., J. M. Romero Sánchez, et al. "Experiences with perinatal loss from the health professionals' perspective, <i>Rev Lat Enfermagem</i> 19(6): 1405-1412	2011	Spain
Puia, D. M., L. Lewis, et al. (2013). "Experiences of obstetric nurses who are present for a perinatal loss." <i>Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns</i> 42(3): 321-331	2013	USA
Roehrs, C., A. Masterson, et al. "Caring for families coping with perinatal loss." <i>J Obstet Gynecol Neonatal Nurs</i> 37(6): 631-639	2008	USA
Saflund, K., B. Sjogren, et al. (2000). "Physicians' role and gender differences in the management of parents of a stillborn child: a nationwide study." <i>Journal of Psychosomatic Obstetrics & Gynecology</i> 21(1): 49-56.	2000	Sweden
Steen, S. E. (2015). "Perinatal death: bereavement interventions used by US and Spanish nurses and midwives." <i>International Journal of Palliative Nursing</i> 21(2): 79-86.	2015	USA/ Spain

Output of search strategy for studies of interventions to maximise wellbeing for bereaved parents and families



Thirty seven relevant studies published between 1994-2014 were identified through the search strategy developed to answer this question. Six more were added by back chaining. Eight studies (all

from HIC's) included experiences of specific groups: fathers;^{37, 77, 187} siblings;^{51, 59, 188} and lesbian couples.¹³⁵ Ten were from LMICs (^{189, 190 191 33, 192-197}). Eighteen studies, all in HICs, assessed aspects of interventions. (*quantitative or mixed methods:* ^{34, 66, 69, 73, 86, 198, 199 190, 191}; *qualitative:* ^{34, 86, 192}including two reviews with no data.^{9, 10}

Table 4 - Studies included in systematic review of interventions to maximise wellbeing for bereaved parents and families

Continent	Authors	Date	Location	Participants	Topic	Design	Sample size	Overall findings (authors interpretation for each study)	Fit with social support taxonomy Tangible/ Esteem/ Information/ Emotion Network/belonging	Sub-category
Europe	Radestad et al ²⁰⁰	1996	Sweden	Mothers	Nationwide study of how stillbirth is managed in Sweden	National survey	314 women who had experienced stillbirth	Nearly every mother had seen her child, and 80 percent had caressed her baby. More than 90 percent of the mothers stated that the medical staff showed respect, and about 80 percent of the mothers stated that staff exhibited tenderness toward their dead children. The mother's assessment of respect and tenderness to her child by medical staff was almost identical between stillbirths and live births. Nearly 70 percent of the women reported that the hospital had good routines to support mothers of stillborn children. Feelings of sadness and having been deeply hurt or angered by the medical staff's behavior were reported by 37 percent of the women. A difficult balance is still to be achieved between women being forced to encounter the baby when not yet ready versus others who wish the staff had given more encouragement. The value of properly taken photographs is described.	Tangible Information Emotion	'What works' from quant data
Europe	Samuelsson et al ¹⁸⁷	2001	Sweden	Fathers	Fathers experiences of losing a child before birth	Phenomenological interviews	11	Most first wanted their partners to have a cesarean section, but all later thought that it would be right for the child to be delivered vaginally. A strong feeling of frustration and helplessness came over them during and after the delivery. Several men found meaning and relief in their grief by supporting their partner. Tokens of remembrance from the	Tangible Esteem Emotion	Special groups (fathers)

								child were invaluable, even if the parents declined them. The prerequisite for resuming their everyday lives was support they received from the hospital staff and precious memories of the child. The most important comfort was a good relationship with their partner. Some missed having a man to talk to both at the time and subsequently.		
Europe	Säflund et al ⁸¹	2004	Sweden	Parents	The role of care givers after a stillbirth: views and experiences of parents	Interviews (x2)	57 interviews (parents of 31 stillborn babies	The six "qualities" that summarized the findings were "support in chaos", "support in the meeting with and separation from the baby," "support in bereavement," "explanation of the stillbirth," "organization of the care," and "understanding the nature of grief."	Tangible Information Emotion	'what works' from qualitative data
Europe	Säflund K, Wredling R. ⁷⁷	2006	Sweden	Couples who had experienced stillbirth	Differences within couples' experience of their hospital care and well-being three months after experiencing a stillbirth.	Questionnaire three months after loss	22 couples	Fathers had the same strong feelings of warmth, pride, tenderness, and grief as the mothers when they held the child.	Emotion	Special groups (fathers)
Europe	Erlandsson et al ⁵⁹	2010	Sweden	Parents (talking about siblings)	Siblings' farewell to a stillborn sister or brother and parents' support to their older children: a questionnaire study from the parents' perspective.	Survey (parents) One year after the birth	16	Seeing and holding the baby Being present at the funeral Visiting the grave/memorial site Physical closeness Time to talk Reading about death and hope Showing feelings Drawings and play	Information Emotion	Special groups (siblings)
Europe	Radestad et al. ²⁰¹	2011	Sweden	Mothers	Evaluation of care after stillbirth in Sweden based on mothers' gratitude	On-line questionnaire	799	Women who gave birth to a stillborn child after 1990 expressed gratefulness more often than women who gave birth to a stillborn child before 1990, for several reasons including the help received in creating memories of their baby. The mothers were thankful for being supported in their motherhood, and that the staff encouraged them to see, hold and be with their baby.	Tangible Information Emotion	'what works' from quant data

Europe	Erlandsson et al. ⁵⁵	2011	Sweden	Parents	Social support	Longitudinal quantitative survey (3 months, 1 year, 2 years after stillbirth)	33 mothers, 22 fathers	Those giving first line support included midwives, physicians, counsellors and priests. The degree to which this was needed might relate to the degree to which family and social network support is available At the two year point support from family and friends was important Family and friends/those in the parents social network may need information to help them to offer effective support in the long-term	Tangible Emotional	Intervention
Europe	Avelin et al. ⁵¹	2011	Sweden	Parents, speaking about the needs of siblings	Swedish parents' experiences of parenthood and the need for support to siblings when a baby is stillborn.	Focus groups (n=6)	27 parents	parenthood is a balance between grief and everyday life'. Support in an acute situation (need for information on how to cope with/help siblings, as well as tangible support, like food and comfort) Sharing the grief with the family (letting the sibling see photos, or the baby him/herself) Adjusting to the situation (including sibs help with/attendance at the funeral)	Tangible Informational Emotional	Special groups (siblings)
Europe	Aho et al. ⁴⁹	2011	Finland	Fathers	General support: Intervention included information on deaths, and the mourning process that might be experienced by all family members; poems and stories; peer support contact; health professional contact; explicit focus on compassion and concern	Comparative cohort (not clear if the clusters were randomized or not)	(n=5 clusters: 2 intervention , 3 control) 62 in the intervention , 41 in control	Higher % of those in the intervention group stated they had support from health personnel and peer supporters. Intervention fathers reported stronger personal growth, and less blame and anger. Other sub-analyses reported. Details of the response to the package also reported. The more contact with health personnel postnatally the more they felt supported. Almost all favoured continuation of the peer supporter support	Information Emotion Network/belonging	Intervention
Europe	Avelin et al. ¹⁸⁸	2012	Sweden	Parents	Parents' advice on how the siblings of a stillborn baby can be	On-line survey (parents)	411 parents	Make the stillborn baby and the loss real for the siblings' 'take the siblings resources and prerequisites into account' Where this is right for them:	Emotional	Special groups (siblings)

					supported.			Sibs should see and hold the baby Sibs should be included in leave taking		
Europe	Cacciatore et al. ³⁷	2013	Sweden	Fathers	Swedish mens' experience of care after the death of a baby	Online survey	131	Most fathers felt grateful overall. Fathers felt negative when providers were nonchalant, indifferent, uncaring, disrespectful Treating new-born with respect not fear/with extraordinary reverence Creating memories When fatherhood was validated	Tangible Emotional Esteem	Special groups (fathers)
Europe	Downe et al. ⁸⁶	2013	UK	Parents	Bereaved parent's experience of stillbirth in UK hospitals	In-depth interviews	25 individuals	Respondents talked about their interactions with hospital staff as having profound effects on their capacity to cope, both during labour and in the longer term. The data generated three key themes: 'enduring and multiple loss'; 'making irretrievable moments precious'; and the 'best care possible to the worst imaginable'. The meta-theme was 'One chance to get it right.'; this referred to the parents and family, clinical and support staff, and the NHS organisations that indirectly provide the resources and governance procedures that may (or may not) foster a caring ethos. Positive memories and outcomes depend as much on genuinely caring staff attitudes and behaviours as on high-quality clinical procedures. A list of useful procedures is also given.	Tangible Information Emotion	'What works' from qualitative data Interventions
Europe	Nikkola et al. ²⁰²	2013	Finland	Mothers	General support: Intervention included information on deaths, and the mourning process that might be experienced by all family members; poems and stories; peer support contact; health professional contact; explicit focus on compassion and concern	Cohort	2 intervention cohorts	Most respondents reported that the support they received helped them in coping. The most emotional support was received from peer supporters and health professionals The intervention was considered to be useful. However, for most measures, less than 60% rated this moderately or highly A range of sub-analyses are reported	Information Emotion Network/ belonging	Intervention

Europe	Erlandsson et al. ³⁸	2013	Sweden	Mothers	Seeing and holding	Online questionnaire	840	Mothers of stillborn babies feel more natural, good, comfortable, and less frightened in the context of assumptive bonding (offering the baby to the mother without seeking her opinion in advance)	Tangible Emotional	Intervention
Europe	Crawley et al. ¹⁹⁸	2013	UK	Mothers	Making and sharing memories	On-line questionnaire survey	162 mothers	Most respondents made and shared memories. The number of different memory-making activities did not affect mental health outcomes The degree to which memories were shared was associated with less PTSD Time since the death of the baby, professional support, sharing of memories, and less wish to talk more were all associated with better mental health	Tangible ? Esteem Informational Emotional Network/ belonging	Intervention
Europe	Avelin et al. ⁸²	2014	Sweden	Adolescent half-siblings	Adolescents experiences of having a stillborn half-sibling	Interviews	13	Being inside family grief, but also outside Important to include even half-siblings in the process	Emotional	Special groups (siblings)
Europe	Ryninks et al. ³⁴	2014	UK	Mothers	Seeing and holding	Interviews 3 months after stillbirth	21	Having contact with their stillborn infant provided mothers with time to process what happened, to build memories, and to say goodbye, often sharing the experience with partners and other family members. Most were satisfied; some felt fear of seeing damage to the baby/ that the baby was dead; some felt strong disbelief/disassociation	Information Emotional	Intervention
N America	Cacciatore,J .Bushfield,S ⁷³	2007	USA	Mothers	Mother's experience and implications for improving care	Open questions on postal questionnaire	47	The findings support the need for perceived psychosocial and spiritual support from professional caregivers, family, and friends. The women's own experiences argue for comprehensive approaches to support the grief and loss of stillbirth, and for the importance of social work involvement in both immediate and longer term interventions. Some women reported finding meaning and purpose over time. Specific interventions that might have helped were information and guidance; timely intervention of caring competent social workers	Tangible Emotion Information	'what works' from qualitative data Intervention

								before hospital discharge; follow up and personalized care		
N America	Cacciatore ¹⁹⁹	2007	USA	Women who had experienced stillbirth	Evaluation of the effects of support groups	Cross sectional mixed methods (multiple surveys)	47	The main outcome measure was the Impact of Event Scale (IES). 29/47 attended local support groups, and had a mean IES-R score of 3.41 /12 vs 7.56 for those never attending. This was significance even controlling for time. Qualitative data supported these findings. (Also evidence of guilt and shame, but also of life changing for the better)	Emotion Network, belonging	Intervention
Multiple (majority USA)	Cacciatore et al. ⁶⁹	2008	Mainly USA (72%), UK, Australia, Canada. 4% elsewhere	Women who had experienced stillbirth	Seeing and holding	On-line survey	2,900 complete surveys	Over 90% of women saw and/or held their baby, and nearly all appreciated this – over 80% of those who did not see/hold their baby regretted it. Women who were not currently pregnant with a subsequent baby had lower anxiety symptoms than those who were currently pregnant/	Tangible Emotional	Intervention
N America	Cacciatore et al. ⁶⁶	2009	USA	Mothers	Are anxiety and depression levels lower in women who had social support after a stillbirth?	On-line survey (closed and open questions)	769 mothers who experienced a stillbirth in the prior 18 months	Women receiving family and social network support were significantly more likely to report lower levels of anxiety and depression. Nurses, physicians and support groups were reported to be helpful, but this didn't reach statistical significant	Tangible ?Esteem Emotional Network/belonging	Intervention
N America	Cacciatore ¹⁰⁰	2010	USA	Mothers	The unique experiences of women and their families after the death of a baby	On-line survey (closed and open questions)	47	Variables that affect women's perceptual experience include social support, legitimization of her loss, opportunities for rituals, and existential emotions such as shame and guilt. Enhanced understanding of the experience and psychosocial support may help some women and their family systems cope with the long-term effects of this loss.	Information Emotion	'what works' from qualitative data
N America	Bennett et al. ²⁰³	2012	USA	Mothers	Psychological intervention based on 'adaptive emotion regulation skills', and finding sources of social support (emotional	Pilot study; randomized to 2wk, 4wk, 6wk waitlist for intervention	5	Steady decline in reported grief symptoms over the time of the intervention, and maintained at 6 week follow up assessment	Emotional Network/belonging	Intervention

					and logistical): 8 weekly one hour sessions					
N America	Pullen et al. ²⁰⁴	2012	USA	Parents	Parents recall about the way they were notified about stillbirth	On-line survey	90 total: 43 with positive recall	Support of parent emotion, continuity of care, and information provision were all viewed positively	Information Emotion	'What works' from qualitative data
N America	Blood and Cacciatore ²⁰⁵	2014	USA	Parents	Best practice for photographs	On-line survey with open and closed questions	104	Best to have many pictures with maximum variety. Some wanted professionals to do this, some wanted to do their own Guidance from staff was requested, with difficult decisions, and to encourage even those who are reluctant to have pictures taken There are a few for whom pictures are culturally unacceptable.	Tangible Informational Emotional	Intervention

Continent	Authors	Date	Location	Participants	Topic	Design	n	Overall findings (authors interpretation for each study)	Fit with social support taxonomy Tangible/ Esteem/ Information/ Emotion Network, Belonging	Sub-category
<i>S America</i>	Santos et al. ¹⁸⁹	2004	Brazil	Mothers	Histories of fetal losses told by women	Oral history via interviews	7	Loss of part of herself; Loss due to divine intervention; Changes in attitude towards life Support from health services practically non-existent. Helpful aspects: Family support (with spiritual belief); Church support/spiritual belief NB evidence that women had gained something from the experience	Emotion Network/belonging	LMIC countries 'What works' from qualitative data
<i>S America</i>	Montesinos et al. ¹⁹⁰	2013	Chile	Parents and care providers	Evaluation of 10 years of a procedures manual and grief support and training programme	Mixed methods, including records analysis, interviews and surveys	Data relating to 440 infants; 51 staff surveys; 16 parents interviews	Warning of impending death, presence of parents at the time of death, having a post-mortem conversation all improved. The % of parents attending the post-mortem did not change. Parents valued seeing and holding, provision of facilities for privacy and comfort, and compassionate caring treatment. One said ' <i>it makes me feel human</i> '	Tangible Informational Emotional	LMIC countries Intervention
<i>S America</i>	Muza et al ¹⁹¹	2013	Brazil	Parents and families	Psychological intervention	Notes review and semi-structured interview	Families of 5 babies (various numbers of family members including grandparents and aunts included in each case)	Results for psychological intervention hard to interpret but some indication that including family members may have reinforced network support	Emotional ? network/belonging	LMIC countries Intervention

Africa	Conry and Prinsloo 192	2008	S Africa	Mothers who had a stillborn baby in the previous 5 years	Experiences of access to supportive services (hospital, religious, formal and social services)	Semi-structured interviews	15	Mothers that received at least some support generally felt better: most cited supportive staff who were compassionate and understanding, and who made opportunities for making memories. Only 1 was offered access to formal counselling. (most findings demonstrated a lack of such support)	Tangible Emotional	LMIC countries Intervention
Africa	Haws et al 193	2010	Tanzania	Women who had infertility, miscarriage, stillbirth or NND; new mothers; female elders	How rural Tanzanian women's experiences of pregnancy loss and early neonatal death may impact survey data quality.	Narrative interviews	95 interviews from 50 women who had infertility, miscarriage, stillbirth or NND; 31 with new mothers and female elders	Stillbirth and early NND are hidden to reduce social and physical harm; women come under strong social control, including advice not to mourn (even though they experience grief). Silence about the loss prevents sorcery, spiritual interference, gossip, stigma (re procuring an abortion/harboring evil spirits: these women are especially denied social support), and social exclusion/divorce.	No data on what works resulted from the study	LMIC countries
Africa	Kuti et al. 194	2011	Nigeria	Mothers	Experiences and needs of Nigerian women after stillbirth	Questionnaire administered by face to face interview	45	Of the 45 women interviewed, 24 (53.3%) were given the opportunity to see the body of their infant. None was given the opportunity to hold, take pictures, or name the infant. Thirty (66.7%) wished they had seen their infant, and 8 (17.8%) and 2 (4.4%) wished that they could have held and taken photographs of their infant, respectively. Only 7 (31.82%) women had fully recovered within 3 years of stillbirth. Contrary to general beliefs, most women wished to see the body of their stillborn infant and many desired to hold them	Tangible Emotional	LMIC countries 'what works' from quant data

Africa	Simwaka et al. ¹⁹⁵	2014	Malawi	Mothers	Women's perceptions of Nurse-Midwives' caring behaviours during perinatal loss	Semi-structured interviews	20 who had a stillbirth in previous 2 years	Almost half satisfied with nurses care Some dissatisfied with degree of attention/information /blamed nurses for the death Basic nursing and physical care and Explanations were valued, and seen as unusual	Tangible Information	LMIC countries 'what works' from qualitative data
Africa	Sisay et al. ³³	2014	Ethiopia	Three generations of women	attitudes and values surrounding stillbirth and neonatal mortality among grandmothers, mothers, and unmarried girls	Focus groups (n=30)	207	These babies are 'strangers in the community' New-born deaths and stillbirths are hidden Baby is buried in the back yard (mourning is not permitted) Homebirth is preferred Women who have SB or NND are to blame (and are dishonored/banished/divorce if they have frequent losses)	No data on what works resulted from the study	LMIC countries
Asia	Hsu et al. ¹¹⁵	2002	Taiwan	Mothers	Transforming loss: Taiwanese women's adaptation to stillbirth	Interpretive ethnography: mainly interviews over 2 years	20	Transforming the meaning of death (spiritual meaning) Doing something for the deceased (memorial acts) Anticipating another pregnancy Rebuilding social fabric (especially with in-laws)	Tangible Emotional Esteem Network/belonging	'what works' from qualitative data
Asia	Ota ²⁰⁶	2006	Japan	Mothers	Mothers' perspectives on care needs after experiencing a stillbirth	Semi-structured interviews	14	(from abstract): The results of the analysis indicated two sub categories and one core category. The first sub-category was " <i>support me becoming a mother</i> " (including seeing and holding, and helping to say goodbye; making mementos; support for cremation and burial; treat my baby as if he was alive) The second was ' <i>support for working through the grief process</i> ' (help with talk out and listen to my stories of my child and my experiences, assurance that it's O.K. to cry and provide an environment where I can cry; an environment that won't add to my pain; after-hospital support and information; support for the family to support the mother).	Tangible Information Emotion Esteem Network/belonging	'what works' from qualitative data

								<i>Work out my wishes and support my decision-making was the overall theme</i>		
Asia	Roberts et al. ¹⁹⁶	2012	India	Mothers	Social and cultural factors associated with perinatal grief	Structured interviews (largely quantitative)	178	Greater grief among women with lack of support, agreement with social norms, and young maternal age NB risk of abandonment/ mistreatment/ divorce in the situation of perinatal loss Improvements in the situation of: Greater support Resistance to social norms that deny the potential to grieve (being older)	Emotion Esteem Network/belonging	LMIC countries 'what works' from qualitative data
Asia	Sutan et al. ⁴⁶	2012	Malaysia	Mothers	Psychosocial impact of perinatal loss among Muslim women	Focus groups and interviews	16	Experiences of a lack of communication and privacy in the hospital Decisions on things like burial depended on the husband Family members and friends were an important source of support Ritual and farewell events helped Reminders that the event was a test from God improved their sense of self-worth	Tangible Emotional Network/belonging	LMIC countries 'what works' from qualitative data
Asia	Sun et al. ³⁰	2014	Taiwan	Parents	Seeing or not seeing the baby: Taiwanese parents experiences following stillbirth	Phenomenology related to seeing/not seeing	12 couples (24 people)	For some, not seeing was a way of protecting against over-attachment, preventing memory imprinting, of avoiding guilt and suffering, 'pretending' event closure, and of following cultural taboos. For others, seeing the baby leads to: Believing Avoiding regret An opportunity to say farewell Imprinting memory (but could also lead to shock reactions)	Information Emotion	LMIC countries 'what works' from qualitative data
Asia	Tseng et al. ³¹	2014	Taiwan	Mothers	Taiwanese women's process of recovery from stillbirth	Interviews	21	Suffering from silent grief Searching for a way out Achieving peace of mind and stability	Emotion	'what works' from qualitative data

<i>Worldwide</i>	Koopmans et al. ¹⁰	2013	All	Parents and families	Social support	Systematic review	No studies included	No data as no studies	N/A	N/A
<i>Multiple</i>	Horey et al. ⁹	2013	all	Parents	Interventions for supporting parents' decisions about autopsy after stillbirth.	Systematic review	No studies	No data	N/A	N/A
<i>Multiple</i>	Badenhorst et al. ²⁰⁷	2006	Multiple countries, ? all HIC	Fathers	The psychological effects of stillbirth and neonatal death on fathers	Review, English language only	17 studies included (4 on fathers only)	Mostly negative: grief and loss	N/A	N/A
<i>Multiple</i>	Peel ¹³⁵	2009	UK, USA, Canada, Australia	Lesbian couples	Pregnancy loss in lesbian and bisexual women: an online survey of experiences	On-line survey	60	Amplified loss due to difficulties in getting pregnant; Some reported discrimination Majority rated care as generally good or very good; 'huge blessing' when female partner was included naturally	Emotional Esteem	Special groups (lesbian couples)

Figure 3 – Locations of studies included in the meta-summaries of direct, indirect and intangible costs of stillbirth. 18 studies were international.

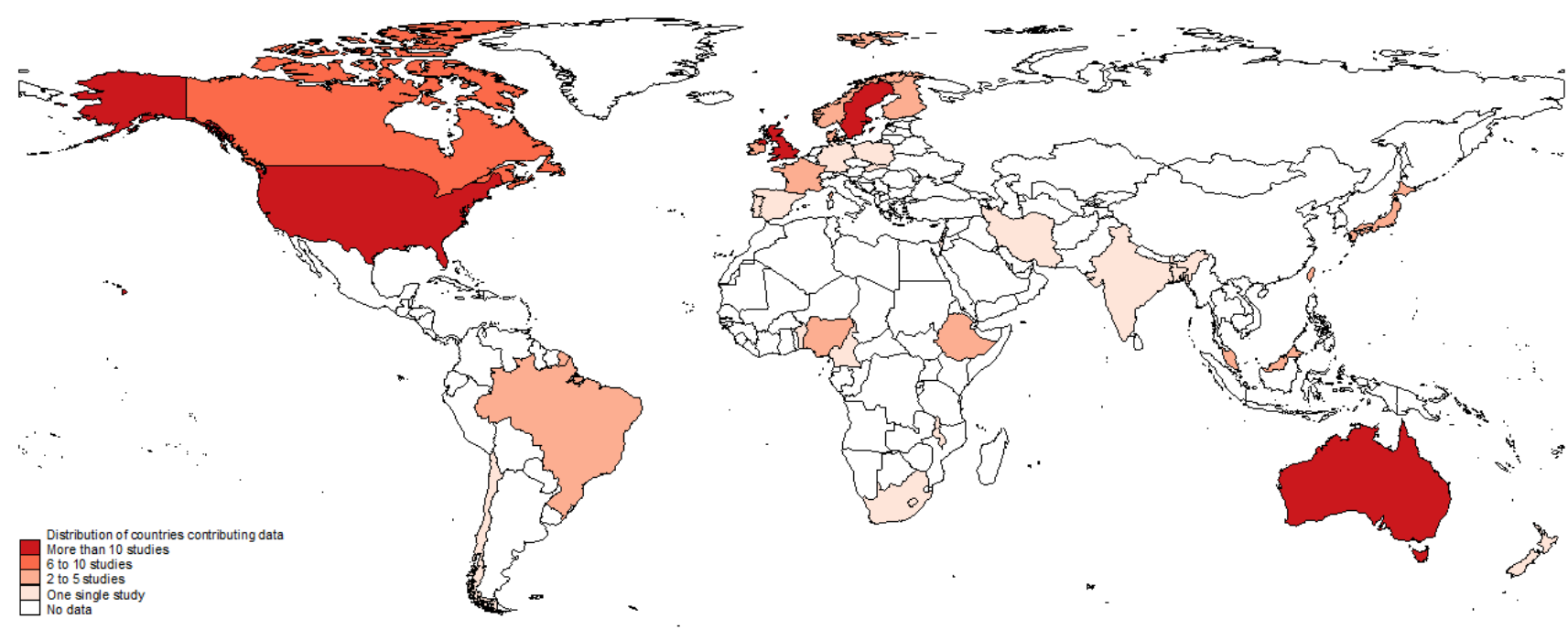


Table 5 - Proportion of parents reporting support-seeking following stillbirth in HIC (N=3503) and MIC (N=679).

Mode of support		More than six occasions	Three to six occasions	One or two occasions	Never
Counsellor / Therapist	MIC	26.6%	14.2%	13.6%	45.5%
	HIC	31.7%	13.2%	20.1%	34.8%
Family doctor	MIC	14.5%	3.4%	30.2%	51.2%
	HIC	9.1%	11.7%	31.9%	47%
Internet forum or phone support	MIC	48.4%	15.3%	19%	16.6%
	HIC	57.2%	11.2%	12.4%	18.5%
Religious leader	MIC	6.3%	6.3%	19.6%	67.7%
	HIC	7%	5.3%	27.1%	59.8%
Bereavement support group	MIC	17.3%	7.4%	12.4%	62.3%
	HIC	20.7%	7.3%	13.1%	58.5%

Proportion of parents responding to the question “Overall, how would you rate the quality of the follow-up care you received from your care providers?”

	Poor or very poor %	Well or very well %
HIC (N=3503)	37.9	39.9
MIC (N=679)	60.1	8.8

Figure 4 – Summary of direct and indirect costs following stillbirth reported by parents from HICs and MICs responding to an international questionnaire. A greater proportion of parents from MICs experienced direct costs associated with stillbirth.

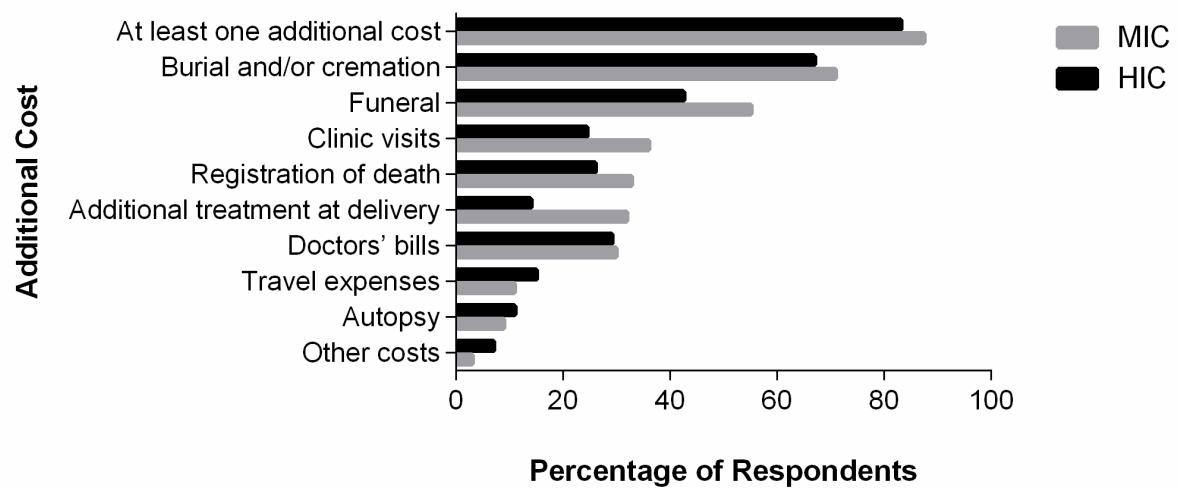


Table 6 - Proportion of parents, care providers and general community members responding to the question “In the community I live/work, people/my colleagues generally think that:”

	Parents				Care providers				General community members			
	MIC (N=679)		HIC (N=3503)		LMIC (N=117) ^α		HIC (N=2020)		MIC (N=318)		HIC (N=1113)	
	Disagree %	Agree %	Disagree %	Agree %	Disagree %	Agree %	Disagree %	Agree %	Disagree %	Agree %	Disagree %	Agree %
Many stillbirths are preventable	25.3	54.5	23.2	29.2	15.4	67.5	30.5	32.8	17.3	61.4	35.6	31.1
A stillborn baby is the same as the death of a child	41.1	53.1	45.2	40.2	33.3	49.6	18.9	69.8	33.8	58.1	25.6	63.3
The death of a baby to stillbirth is “nature’s way”	39.7	36.5	31.5	33.9	58.1	12.8	51.2	13.5	52.5	19.4	46.2	20.9
The death of a baby to stillbirth is usually the mother’s fault	49.4	28.3	62.9	12	72.6	4.3	94.1	0.5	81.5	2.5	88.3	3.33
Parents should try to forget their stillborn baby and have another child	50.8	44.3	42	42.7	59.8	25.6	88.2	3.2	56.2	26.8	69.1	17.1
Parents should not talk about their stillborn baby because it makes people feel uncomfortable	47	42.6	40.6	45.3	76.1	12.0	90.4	3.9	73.9	25.6	75.6	15.9
Parents should be able to grieve openly after their baby is stillborn	41.8	47.9	33.4	43.2	17.1	65.8	5.7	86.4	26	57.1	20.3	68.1
Parents get the care and support they need when their baby is stillborn	61.5	15.1	36.4	31.5	30.8	49.6	17	59.7	72	17.8	51.7	22.6
There is a lack of awareness of stillbirth	14	77.4	9.9	75.1	23.1	56.4	22.6	61.7	8.5	74.9	11.4	73.3

^α Unweighted data

Table 7 - Proportion of parents responding to the question “After your baby was stillborn, were you given the opportunity:”

	Yes, and I'm glad I had the opportunity		Yes, but I did not want the opportunity		No, but I would have liked the opportunity		No, but I did not want the opportunity	
	MIC (N=679)	HIC (N=3503)	MIC (N=679)	HIC (N=3503)	MIC (N=679)	HIC (N=3503)	MIC (N=679)	HIC (N=3503)
	%	%	%	%	%	%	%	%
to spend time with your baby?	45	77.6	5.2	5.3	31.2	12.1	10.3	2.4
to see and hold your baby?	51.2	80.7	5.2	5.3	25.1	9.2	9.6	2.5
for other family members or friends to meet your baby?	55.9	64.6	7.2	8.4	20	14.3	7.2	9.8
to create memories of your baby (e.g. photos, finger prints, hand prints)?	34.5	71.7	4	1.1	49.4	21.1	3	3.9
to name your baby?	78.4	86.5	<0.1	1	14.4	8.9	0.6	1.4
to take your baby home?	21.3	9.5	3.4	6.7	36.6	35.5	26.3	41.7
to have a funeral (or other service or ceremony) for your baby?	67.9	76.2	8.1	7.7	9.2	9.2	7.5	4.6

Table 8- Proportion of parents, care providers and general community members responding to the question “At your facility, are parents who have a stillborn baby given the opportunity:”

	Never		Some of the time		Most of the time		Always	
	LMIC ^α (N=117)	HIC (N=2020)	LMIC ^α (N=117)	HIC (N=2020)	LMIC ^α (N=117)	HIC (N=2020)	LMIC ^α (N=117)	HIC (N=2020)
	%	%	%	%	%	%	%	%
to spend time with their baby?	24.8	1.6	35.0	4.1	17.1	12.6	17.9	81.3
to see and hold their baby?	17.1	1.5	35.9	2.9	19.7	15.7	22.2	79.5
for other family members or friends to meet their baby?	37.6	3.4	8.5	8.7	7.7	17.5	7.7	65.6
to create memories of their baby (e.g. photos, finger prints, hand prints)?	31.6	4.2	27.4	7.2	19.7	11.1	15.4	75.9
to name their baby?	33.3	4.3	18.8	8.3	15.4	10.9	22.2	73.3
to take their baby home?	43.6	22.3	13.7	11.8	12.0	13.6	25.6	36
to have a funeral (or other service or ceremony) for their baby?	17.1	8.2	17.9	5	20.5	11.4	34.2	71.7

^α Unweighted data

Remainder were unsure or preferred not to answer

Thematic analysis of free-text responses to the 2015 Lancet Stillbirth Series Questionnaire

The frequency of themes was determined by two researchers, the average frequency with which each theme occurred is shown in the tables below. These data highlight the importance of wider family and peer support following the experience of stillbirth amongst respondents.

Theme	Average count	%
Family (including parents & siblings)	1194	28.5
Support group (includes social media/ forums/ blogs/ apps/ networking)	1124	27.9
No support	1012	24.2
Friends	730	17.5
Other mums/similar others/family members who'd had a similar experience	439	10.5
Partner	388	9.3
Psychologist/psychiatrist/psychotherapist/therapist	343	8.2
Healthcare professional (includes midwife/obstetrician/IVF company/ nurse/ GP /social worker/ gynaecologist/ paediatrician/ pathologist/ consultant/ matron/ geneticist)	251	6.0
Church (includes faith/spiritual/belief/priest/pastor/deacon/prayer/God)	85	2.0

When free-text comments described whether this means of support was helpful or unhelpful this was noted. The majority of comments for each theme were positive (e.g. "I could not have coped during this time if it wasn't for my family"). However, a minority of comments were negative (e.g. "My family felt that I had grieved for long enough, and couldn't understand my feelings").

Theme	Helpful Average Count	%	Unhelpful Average Count	%
Support group (includes social media/ forums/ blogs/ apps/ networking)	472	11.3	20	0.5
Family (includes parents and siblings)	439	10.5	47	1.0
Friends	286	6.8	19	0.5
Other mums/similar others/family members who'd had a similar experience	208	5.0	-	-
Partner (includes husband/wife/girlfriend)	197	4.7	-	-
Healthcare professional (includes midwife/obstetrician/IVF company/ nurse/ GP/ social worker/ gynaecologist/ paediatrician/ pathologist/ consultant/ matron/ geneticist)	130	3.1	33	0.8

Psychologist/psychiatrist/psychotherapist/therapist	112	2.7	-	-
Church (includes faith/ spiritual/ belief/ priest/ pastor/ deacon/ prayer/ God)	37	0.9	-	-

When parents responded to the question asking “Is there anything you would like to tell us about the financial costs, impacts or effects of having a stillborn baby?” 13.3% noted that they had not incurred any additional costs; some noted with gratitude that this was a relief. Similarly, other respondents had bereavement benefit or payment to cover at least some of the costs incurred. However, other parents noted the significant financial impact that having a stillborn child or children had made on their lives. Some explicitly stated that the ongoing repayments provided a continuous reminder of the death of their child.

Theme	Average count	%
No costs incurred	555	13.3
Financial impact (includes debts, long-term impact)	267	6.4
Bereavement benefit / payment	182	4.6
Loss of income/work/unpaid time off work	170	4.1
Funeral costs/headstone/urn/coffin	126	3.0

Financial costs extracted from the 2015 Lancet Stillbirth Series Questionnaire

Data regarding costs incurred after stillbirth were extracted from the free text responses to the question “Is there anything you would like to tell us about the financial costs/impacts/effects of having a stillborn baby?” These cost data were given in their local currencies, these were converted using the appropriate exchange rates and presented to the nearest US dollar.

Table 9 – Financial costs incurred by parents extracted from the 2015 ISA survey

Theme	No of responses	Examples of costs	US \$ 2013
Headstone/ gravestone	42	Canada (Canadian \$)	2000
		Denmark (Danish Krone)	8,000kr
		Germany (Euros)	€3,500
		Norway (Norwegian Krone)	22000NKR
		UK (£ Sterling)	£1000
			1,980
			1,410
			4,605.26
			3,793.10
			1,562

		USA (US \$)	\$2500	2,500
Counselling/psychologist/ psychotherapist	40	USA (US \$) Colombia (Columbian Peso per month)	\$10,000 \$700mnth	10,000 0.37
Pathology / bloods / tests / amniocentesis	32	Australia (Australian Dollars) Australia (Australian Dollars) Italy (Euros) Spain (Euros) USA (US \$)	800 3000 €150 €2000 \$400	825 3,093 197 2,632 400
Loss of income	19	75% usual pay (Canada)	75% usual pay Canada)	
Burial plot/ grave	18	Germany (Euros) Germany (Euros) UK (£ Sterling) UK (£ Sterling) Argentina (Peso)	€820 €1600 £4000 ; £800 ; 60,000	1079 2105 6250 1250 11605
Hospital fees	12	Germany (Euros) USA (US \$) USA (US \$)	€90 \$20,000 \$600	118 20000 600
Coffin/ casket/basket	11	Germany (Euros) USA (US \$)	€800 \$80	1053 80
Birth cert/ registration	8	Australia (Australian Dollars) Ireland (Euros)	20 €120	21 158
Funeral	6	Australia (Australian Dollars) Australia (Australian Dollars) Austria (Euros) Germany (Euros) Germany (Euros) Ireland (Euros) Italy (Euros) Netherlands (euros) Norway (US \$) UK (£ Sterling) UK (£ Sterling) USA (US \$)	2000 5000 €2500 €7,000 €1500 €5000 €1350 €5000; \$USD £300 £7500 \$500	2062 5155 3289 9211 1974 6579 1776 6579 2200 469 11719 500
Car parking	5	UK (£ Sterling) UK (£ Sterling)	£400 (UK); £99 (UK)	625 155
Newspaper ad	5	USA (US \$)	\$50 (US)	50
Cremation	4	Denmark (Danish Krone) Italy (Euros) New Zealand (NZ \$)	20,000kr; €500 \$60 (NZ)	3515 658 51
Other operations/ treatment post-natal	3	USA (US \$)	\$50,000	50000
Autopsy findings/ fees	2	Netherlands (Euros) Argentina (in US\$)	€230 \$1500	303 1500
Ambulance	2	Spain (Euros)	€1000	1316
Further IVF treatment	1	Spain (Euros)	€30000	39474
Prep for living baby	1	UK (£ Sterling)	£2000	3125
Centrelink bill	1	Australia (Aus. \$)	1750 Aus. D	1804

Table 10 - Details for conversion of local currency into US Dollars.

Conversion factor for 2013 by country to US dollars	Figure	Source
Canada	CAD 1.01	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=CAD&inputDate=29-04-2013&submitConvert.x=264&submitConvert.y=8
Denmark	DEM 5.69	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=DKK&inputDate=29-04-2013&submitConvert.x=223&submitConvert.y=7
Germany	€ 0.76	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=EUR&inputDate=29-04-2013&submitConvert.x=233&submitConvert.y=5
Ireland	€ 0.76	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=EUR&inputDate=29-04-2013&submitConvert.x=227&submitConvert.y=18
Norway	NOK 5.80	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=CAD&inputDate=29-04-2013&submitConvert.x=264&submitConvert.y=8
Colombia		http://www.oanda.com/currency/average
Argentina	ARS 5.17	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=ARS&inputDate=29-04-2013&submitConvert.x=232&submitConvert.y=13
Australia	AUD 0.97	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=AUD&inputDate=29-04-2013&submitConvert.x=299&submitConvert.y=14
Netherlands	€ 0.76	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=EUR&inputDate=29-04-2013&submitConvert.x=227&submitConvert.y=18
Italy	€ 0.76	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=EUR&inputDate=29-04-2013&submitConvert.x=227&submitConvert.y=18
New Zealand	NZD 1.17	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=NZD&inputDate=29-04-2013&submitConvert.x=274&submitConvert.y=11
Spain	€ 0.76	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=EUR&inputDate=29-04-2013&submitConvert.x=227&submitConvert.y=18
UK	£ 0.64	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=GBP&inputDate=29-04-2013&submitConvert.x=191&submitConvert.y=9
U.S.	\$ 1.00	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=USD&inputDate=29-04-2013&submitConvert.x=244&submitConvert.y=3
Austria	€ 0.76	http://sdw.ecb.europa.eu/curConverter.do?sourceAmount=1.0&sourceCurrency=USD&targetCurrency=USD&inputDate=29-04-2013&submitConvert.x=244&submitConvert.y=3

Figure 5 – Location of countries with legal provision for parental leave following stillbirth or miscarriage

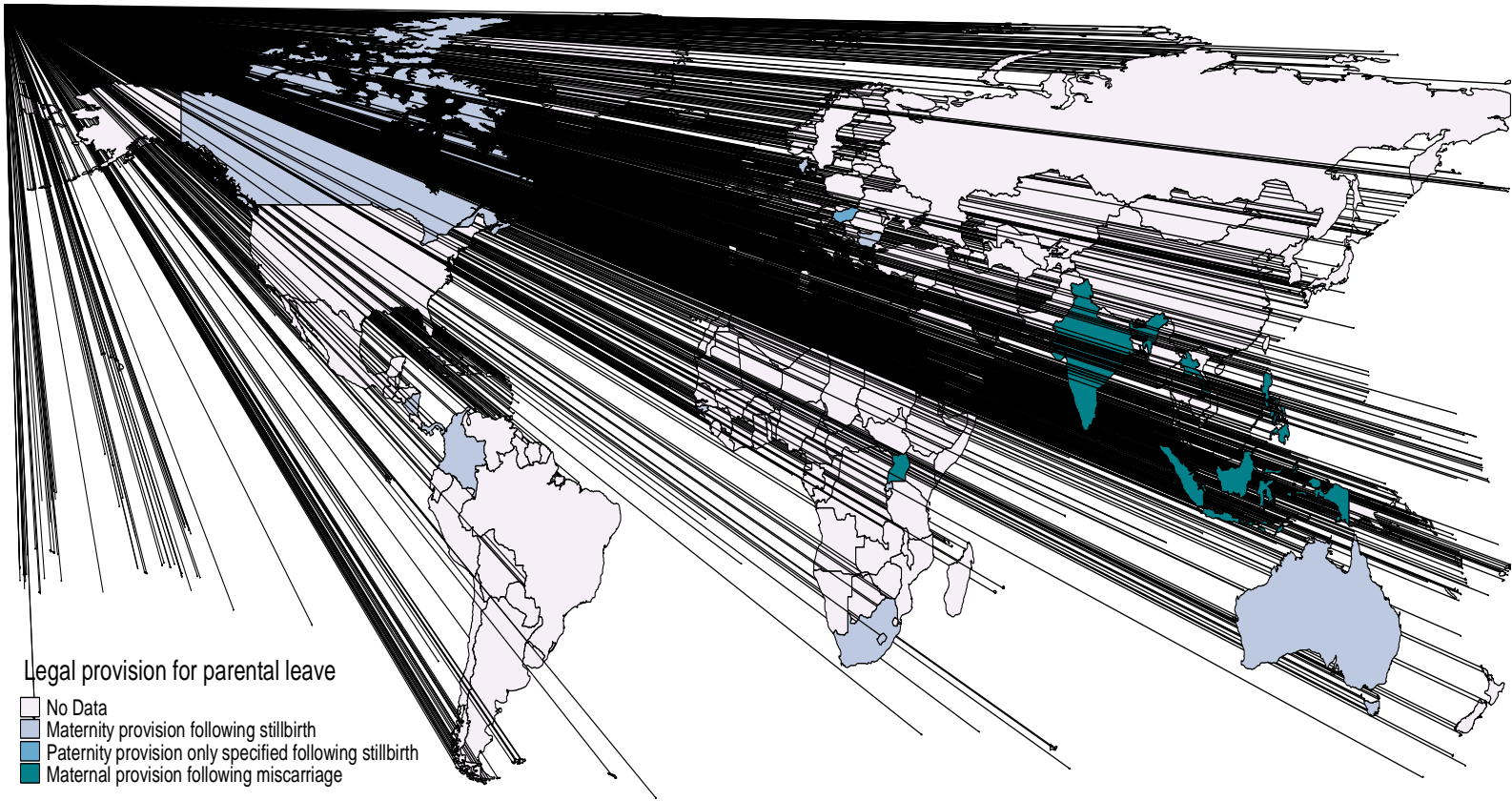


Table 11- Details of maternity and paternity leave for stillbirth identified by the ILO database.

REGION (# COUNTRIES WITH DATA)	MATERNITY LEAVE	COUNTRY	MATERNITY LEAVE PROVISION	PATERNITY LEAVE PROVISION
Africa (51)	Includes stillbirth	Guinea-Bissau	Every female worker is entitled to a maternity leave of 60 days, without loss of remuneration, during the whole pregnancy and in cases of delivery of stillborn, or death of living birth.	
		Rwanda	A woman who delivers a still-born or whose infant of less than one month of age is dead shall benefit from a leave of four (4) weeks as of the day the event occurred.	
		South Africa	6 weeks leave (not specified if paid)	
		Mauritius	Domestic workers - 2 or 12 weeks paid leave	
	Includes provision following non-specified miscarriage	Uganda	In the event of sickness arising out of pregnancy or confinement, affecting either the mother or the baby, and making the mother's return to work inadvisable, the right to return shall be available within eight weeks after the date of childbirth or miscarriage.	A male employee shall, immediately after the delivery or miscarriage of a wife, have the right to a period of four working days paid leave from work yearly herein.
Asia (28)	Includes stillbirth	Australia	Special unpaid maternity leave can be taken by a female employee for a pregnancy related illness, or to recover from a still birth or miscarriage that occurs up to 28 weeks before the expected date of birth. The entitlement to special unpaid maternity leave exists for as long as the employee is not fit for work. The employee must give her employer notice of the need to take special unpaid maternity leave as soon as practicable and must provide evidence of the illness, still birth or miscarriage if required.	
		India	No woman shall work in any establishment during the 6 weeks immediately following the day of her delivery or miscarriage. In the case of a miscarriage, a woman shall, upon production of prescribed proof, be entitled to leave for a period of 6 weeks immediately following her miscarriage. Such leave shall also be paid at the rate of the maternity benefit.	

		Philippines	Employees whose entitlement to maternity arises under the Labor Code or the Batas Kasambahay Act are entitled to maternity leave of at least 2 weeks prior to the expected date of delivery and another 4 weeks after normal delivery or abortion. Government employees are entitled to 60 days' maternity leave.	To qualify for paternity leave, the male employee must: (i) be married to, and living with, the pregnant woman; (ii) be expecting one of his wife's first 4 childbirths or miscarriages; and (iii) notify his employer of the pregnancy and the expected date of delivery.
		Indonesia	There is no general entitlement to leave in the case of any pregnancy-related illness or complication. However, a female worker/labourer who has a miscarriage is entitled to a period of leave of one-and-a-half months, or a period of leave as stated in the medical statement issued by the obstetrician or midwife.	Workers/labourers are allowed to absent themselves from work in the event that their wife gives birth or suffers a miscarriage.
		Lao	No provision for leave in the case of illness or complications during pregnancy identified, beyond the generally-applicable right to sick leave on full pay for up to 30 days per year. In the event that a woman worker is ill as a result of giving birth, and her illness is certified by a doctor, such worker shall be authorised to take additional leave of at least 30 days with payment of 50% of her salary or wages. In the event that the woman worker suffers a miscarriage, she is entitled to take leave for a certain period as determined by a doctor	
Arab States (10)	Includes stillbirth	NONE		
	Includes provision following non-specified miscarriage	NONE		
Europe (47)	Includes stillbirth	Bulgaria	In case of still-birth, of infant death, or if the child is given up to a child-care establishment in the entire care of the State or for adoption, the mother shall be entitled to a leave of 42 days after the date of childbirth. The medical authorities may extend this period in the event they find the mother's ability to work has not been fully restored after the childbirth, up to her complete recovery.	
		Denmark	If child is stillborn or given up for adoption within 32 weeks after the birth the mother has right to 14 weeks of daily benefits. In the case of illness or complications of the mother, she has right to daily benefits for a maximum of 46 weeks after giving birth.	

		Hungary	Upon the birth of his child, a father shall be entitled to five days of extra vacation time, or seven working days in the case of twins, until the end of the second month from the date of birth, which shall be allocated on the days requested by the father. Such leave shall be provided also if the child is stillborn or dies.
	Includes provision following non-specified miscarriage	NONE	
Americas (34)	Includes stillbirth	Canada (Ontario only)	Ontario. Six weeks after the birth, still-birth or miscarriage for employees who are not taking parental leave.
		Colombia	There is a leave in case of miscarriage or premature stillbirth, female workers are entitled to paid leave for two up to four weeks.
		Nicaragua	In the case of miscarriage, stillbirth or other abnormal confinement, the woman worker shall be entitled to paid leave in accordance with the requirements of the medical certificate.
		Panama	In the case of a miscarriage, still-birth or other pathological or abnormal confinement, the paid maternity leave shall be fixed as necessitated by the employee's state of health, on the basis of the medical certificate.
	Includes provision following non-specified miscarriage	NONE	

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